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The impact of child's functional severity on parental coping in two cohorts: children with juvenile idiopathic arthritis and children with physical disabilities

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The impact of child's functional severity on parental coping in two cohorts: children with juvenile idiopathic arthritis and children with physical disabilities

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RÉSUMÉ

Les parents d'enfants atteints de conditions chroniques font face à des demandes plus ardues que les parents d'enfants en bonne santé. « Faire face » représente les efforts cognitifs et comportementaux adoptés par le parent pour réduire ou pour gérer les demandes appliquées sur le système familial. Les objectifs de cette recherche sont de décrire comment les parents d'enfants atteints d'une incapacité physique font face à leur situation familiale et de déterminer si la sévérité fonctionnelle de l'enfant a un impact sur les comportements à « faire face » utilisés par les parents. Les parents (mère ou père) de 182 enfants atteints d'arthrite juvénile idiopathique (AJI) et les parents (mère ou père) de 150 enfants atteints d'incapacités physiques (IP) variées ont participé. Les parents ont complété un questionnaire décrivant leurs comportements à « faire face » (Coping Health Inventory for Parents). La sévérité fonctionnelle pour les enfants atteints d'AJI a été mesurée par le Juvenile Arthritis Quality of Life Questionnaire et pour ceux atteints d'IP par la Mesure d'indépendance fonctionnelle pédiatrique. Les parents de la cohorte AJI ont trouvé plus utile de mieux comprendre la situation médicale pour « faire face » à leur situation, tandis que les parents d'enfants atteints d'IP préfèrent rechercher un support social. Les parents d'enfants atteints d'AJI avec une incapacité psychosociale perçue comme sévère et ceux d'enfants atteints d'IP avec une incapacité perçue comme modérée à sévère au niveau de la mobilité trouvent utile de mieux comprendre la situation médicale (coefficient β de 0.73, IC, 0.01, 1.45 et coefficient β de 2.07, IC, 0.37, 3.78, respectivement). Les parents des deux cohortes ont trouvé utiles divers comportements reliés à « faire face ». La sévérité fonctionnelle de l'enfant est associée au choix des comportements à « faire face » des parents. Ces résultats soulignent davantage le rôle que jouent les professionnels de la santé dans le maintien du fonctionnement de la famille et l'influence que leur implication a sur le bien-être de l'enfant.

Mots clés: « Faire face », parents, enfants, condition chronique, sévérité fonctionnelle, incapacités physiques, arthrite juvénile idiopathique

ABSTRACT

Parents of children with a chronic condition must cope with greater demands than those living with a healthy child. Parental coping refers to the parent's specific cognitive and behavioural efforts to reduce or manage a demand on the family system. The objectives of this research were: to describe parental coping in two separate cohorts and to determine whether the child's functional severity is associated with parental coping. The two cohorts consisted of parents (mother or father) of 182 children with juvenile idiopathic arthritis (JIA) and parents (mother or father) of 150 children with a physical disability (PD). Parents in both cohorts completed the Coping Health Inventory for Parents describing preferred parental coping behaviours. Disease severity for children with JIA was measured by the Juvenile Arthritis Quality of Life Questionnaire and for children with PD by the Functional Independence Measure for children. The coping pattern related to Understanding the Medical Situation was found most useful by parents of children with JIA and Maintaining Social Support was found most useful by parents with children with PD. Parents of children with JIA with greater psychosocial dysfunction used more coping behaviours related to Understanding the Medical Situation (β coefficient, 0.73; 95% CI, 0.01, 1.45), whereas parents of children with PD who presented with moderate to severe disability in mobility also found Understanding the Medical Situation most useful (β coefficient, 2.07; 95% CI, 0.37, 3.78). Parents from each cohort deemed different parental coping patterns useful. Child's functional severity was associated with parental coping. These results further emphasize the role that healthcare providers play in helping to maintain family functioning and ultimately the child's well-being.

Keywords: Coping, parents, children, chronic condition, functional severity, physical disability, juvenile idiopathic arthritis

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LIST OF ABRREVIATIONS

AJC	Active joint count
CHAQ	Childhood Health Assessment Questionnaire
CHIP	Coping Health Inventory for Parents
CI	Confidence interval
CP	Cerebral palsy
DF	Degrees of freedom
DSM-IIIR	Diagnostic and statistical manual of mental disorders version III-R
DSM-IV	Diagnostic and statistical manual of mental disorders version IV
ESR	Erythrocyte Sedimentation Rate
FAAR	Family Adjustment and Adaptation Response
FES	Family Empowerment Scale
GDD	Global developmental delay
GSI	Global Severity Index
HRQL	Health related quality of life
JAQQ	Juvenile Arthritis Quality of life Questionnaire
JIA	Juvenile idiopathic arthritis
JRA	Juvenile rheumatoid arthritis
NCHS	National Centre for Health Statistics
PD	Physical disability
PSD	Positive Symptom Distress
PST	Positive Symptom Total
PT	Physiotherapy
OT	Occupational therapy
SCL-90-R	Symptom Checklist 90 revised
SD	Standard deviation
SPSS	Statistical package for the social sciences
VAS	Visual analog scale
WeeFIM	Functional Independence Measure for children
WCQ	Ways of Coping Questionnaire

To my family for always
believing in me and to
Matthew for his tremendous
support and understanding.

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CHAPTER 1- INTRODUCTION AND STUDY OBJECTIVES

1.1 Introduction

Caring for any child is difficult; caring for a child with a chronic condition can be especially taxing for parents (1). Many studies have examined how living with a child with a chronic condition exacerbates parental stress levels and hinders psychological adjustment (2-8), but little is known regarding the effect of the child's functional severity on parental coping (6). Tak et al. showed no significant association between parental coping behaviours measured by the Coping Health Inventory for Parents (CHIP) and severity of the child's congenital heart disease (6). However, parents may cope differently irrespective of their child's functional severity; accordingly, some families adapt better than others when faced with similar stressors. A study by Daltroy et al. showed that maternal mood was more negatively influenced for those living with a child with juvenile arthritis who was mildly affected compared to those living with a child who was unaffected or moderately to significantly affected (9). Findings from Noojin et al. showed no significant association between the child's functional severity or the child's type of condition with reported maternal adjustment (10). These results suggest a non-linear relationship between maternal mood and severity of the child's functional severity. Law et al. proposed that functional ability was a primary factor in determining the chronically ill child's participation (11). The ability to complete age-appropriate social and physical activities (12-14), may in turn, have an effect on maternal mental health (15).

In light of the similarities between the impact on participation in self-care tasks, school and leisure activities of various physical chronic conditions on both the parent and children, certain authors have suggested that the psychological impact rather than their child's specific medical diagnoses would have implications for parental adjustment (16;17). Many studies report associations between parental stress level and living with a chronically ill child (3;4;6;15;18) although the results have been conflicting. Few however explore the impact of functional severity of the child's disease on the use of parental coping behaviours.

This will be examined in our study by exploring the association between severity of the child's dysfunction and parental coping in two separate cohorts of children: 1) children with juvenile idiopathic arthritis (JIA) and 2) children with physical disabilities (PD).

1.2 Objectives

The main objectives of this study are: 1) to describe and compare parental coping patterns in two different pediatric cohorts: children with juvenile idiopathic arthritis (JIA) and children with physical disabilities (PD) referred to occupational and/or physical therapy; 2) to determine if severity of the child's condition is associated with parental coping in both the JIA and the PD cohorts; 3) to explore other factors (e.g. socio-economic status and family dynamics) related to parental coping in both the JIA and PD cohorts. The secondary objective is: to determine whether severity of the child's condition and socio-demographic characteristics of

the child, the parent and the family environment are associated with a) psychological distress in parents of children with JIA; b) parental empowerment in parents of children with PD.

1.3 Hypotheses

1) Parental coping patterns will vary in usefulness between the JIA and the PD cohorts;
2) Severity of the child's condition will not be associated with parental coping in either cohort;
3) Socio-demographic characteristics of the child, the parent and the family environment will influence parental coping. Specifically, mothers with a lower level of education will find social support coping behaviours most useful;
4) Parental psychological distress and parental empowerment will both be influenced by severity of the child's condition in the JIA and PD cohort, respectively.

CHAPTER 2 - REVIEW OF PERTINENT LITERATURE

2.1 Children with chronic conditions

According to the National Centre for Health Statistics (NCHS) a childhood condition is considered chronic if symptoms are experienced for over three months, or the expected duration is longer than three months (19). Certain definition also include functional status and participation in age-appropriate activities (20;21). Chronic physical conditions can cause an abundance of problems and put the ill child at risk for developing psychological maladjustment (22). These conditions require parents provide regular care to their children possibly leading to parental strain (23). Cadman at al. showed that 10-20% of children in Western developed countries have a chronic disorder (i.e. cognitive, physical and/or persisting medical conditions) (24). In three out of five children, chronic health conditions limited activities (25).

2.1.1 Juvenile Idiopathic Arthritis (JIA)

Juvenile idiopathic arthritis (JIA) is one of the most common rheumatic chronic illnesses of childhood (26;27). It is a heterogeneous group of conditions characterized by inflammation of the connective tissues (e.g., the joints) (28), and for most requires regular follow-up with healthcare professionals and a strict regimen of medication, exercise and splinting (29;30). JIA affects children throughout childhood and into adulthood (31).

Children affected by JIA report chronic pain, stiffness in joints, fatigue, limitations in mobility which may limit their participation in daily activities and possibly lead to permanent disability and deformity (32;33). In JIA, pain occurs because of tissue inflammation of the musculoskeletal system, blood vessels, and skin (34). Recent studies have shown that mild to moderate intensity pain is quite common in children with JIA (35) and occurs on a weekly basis for many children (33). Unfortunately close to 10% of children with JIA will experience severe functional disabilities as adults (27). This disease can cause ongoing strain in the child's life and hinder social functioning over time (36). Furthermore, these children's social integration is directly influenced by mother's level of depression (32;33). Conversely, the better mothers master the demands of the stressful situation, the less distressed the child is (37).

2.1.2 Physical Disabilities (PD)

Disability is defined as the substantial and long-term adverse affect a physical or mental impairment has on the person's ability to carry out day-to-day activities (38). Different diagnoses are associated with some level of physical delay, such as global developmental delay or other pathologic diagnosis including genetic syndromes (e.g. Trisomy 21), neonatal seizures, cerebral palsy, spina bifida and prematurity.

Children with physical disabilities require long-term rehabilitation services and show greater social isolation and limited participation in age-appropriate activities including community and school-based activities (21), which is directly related to the child's physical functioning (11;39). Also, children with physical health conditions and disabilities are more susceptible to experience mental health problems (39).

Finally either JIA or physical disabilities have an impact on the parent and the family. In fact, many studies underscore the importance of parents' support in maintaining adjustment in the chronically ill child (4;22;32;37;40). These parents are often faced with heavy physical and psychosocial demands (41-43). In turn, the demands of the child's chronic condition may impact on parents' ability to care for their child and possibly affect their child's well-being. Furthermore, these children are at greater risk of maladjustment and poor social integration if their mothers have lower educational levels and if families are poorly organized (22). It is important to explore how the child's chronic condition can influence parent's coping behaviours in order to limit the negative effects on both the child and the family.

2.2 Impact on the family

Living with a child with a chronic condition has the potential to change the family dynamics and may have long-term effects on the family system (44;45). In

fact, parents living with a child with a chronic condition or disease are exposed to greater physical, emotional and social demands in comparison to those living with a healthy child (42). In addition, parents must contend with the ongoing strains of every day life, such as ongoing conflicts amongst spouses or other members of the family and the day to day financial burdens.

Mothers of children with chronic conditions such as spina bifida must provide their child with regular assistance with mobility and self-care (41). This must then be incorporated into their already hectic daily routines (41) which may affect family functioning and well-being (46). In 2001, about 35,000 (23%) Canadian children with disabilities required help with their daily activities because of their chronic physical limitations (25). In most cases, the burden of care was absorbed by the parents, mostly by mothers who were the main caregivers in 62% of the cases (25). Most of the help that children received with everyday activities involved personal care (22% of children) (25). The more severe the physical and functional limitations for the child, the greater the burden of care on the parents (41). Mothers of children with disabling physical conditions requiring help with transfers were more prone to developing lower back pain in comparison to mothers caring for children with non limiting medical conditions (43). Mothers of children with chronic medical conditions display lower levels of physical functioning versus those with healthy children (42).

Parents caring for children with chronic illnesses often experience excessive levels of stress (16;17;47-49). Stress is identified by the parent when the demands of the environment exceed the family's resources or endanger their well-being (45;50). The effects of stress are directly linked to coping.

Maternal depression appears to be positively correlated to the child's level of dysfunction (51). Poor psychosocial function, defined as the inability to participate in age-appropriate school and leisure activities, in children with juvenile rheumatic disease may impact parental depression, parental distress level and may increase emotional strain (15). Parents of children with a chronic condition are at greater risk of becoming psychologically distressed (52). Heiman showed that 23.1% of parents caring for children with different cognitive, physical and learning disabilities claim that their child's disability was detrimental to their marital relationship by causing new problems and conflicts between the parents (53). The presence of a child with a chronic condition affects the parents' social activities and relationship with friends (53).

In addition, parents must contend with expected changes, which occur in every family and cause short term effects (e.g. another sibling starting school, father or mother starting a new job) (46). The accumulation of demands that the family must face can include other stressor events and hardships (e.g. loss of a family member, loss of a job), day to day stress (e.g. caring for other siblings,

working) and prior strains impacting the parents and other family members (e.g. poor dynamics between parents) along with the new stressor (45).

Most studies researching family adaptation to living with a child with a chronic health condition are focused on the parent's reactions. However, parental adaptation to the situation can also affect other family members. Healthy siblings must also adapt their schedules to meet the needs of the ill child's appointments and treatment regimen. Cate et al. showed that the relationship between siblings of children with physical disabilities was altered because of the child's disability (54). Siblings may be exposed to greater levels of distress when living with an ill child. They are exposed to strangers' negative reactions, are limited in their activities and are also prone to worry about their sibling's health and well-being (54). A study on children with cystic fibrosis and their families brought up concerns regarding the healthy child's development because parents tended to spend more time with the ill child and much less with their other children (55). Family members may adopt different coping responses to deal with the ill child's condition and their stressful family situation (56).

2.3 Stress and coping theories

In general, stress and coping theories illustrate the person's stress-response process (50). They support coping as transactional in that the person and the environment are viewed as being involved in a bi-directional process by which the

person uses various behaviours to react to the stressful situation. In our study, we are interested in how a family reacts to the stresses brought upon by caring for a child with a chronic condition and in the associated theories.

Family stress theorists (44;57) use various conceptual frameworks to explain the impact of the stressors felt by families living with a child with a disability and the support resources that these families use to positively adapt to those stressors (58). These theorists posit that the person's internal resources (e.g. sense of control, mastery, and self-esteem) used to deal with stressors may influence appraisal (i.e. assessment) of said stressors. These internal resources then contribute to either a positive outcome (family adaptation) or a negative outcome (family crisis).

Many different models have been constructed to illustrate the family's response to a stressful situation. Hill's (1949) ABCX family crisis model and McCubbin et al.'s more recent Double ABCX model were the first models to have conceptualised the family's pre-crisis reaction (57;59). These were developed by studying families' long-term responses to crisis during times of war.

More recent contributions by Wallander et al., in the form of the Disability-Stress-Coping Model, illustrate the mother's adjustment to living with a child with a chronic physical condition as a function of stress and the family (60). This theoretical model identifies main risk (e.g. child's diagnosis) and resistance factors

(e.g. problem solving abilities) and examines how these factors relate to each other as well as their direct and combined effects on maternal adaptation (60), without however specifying the coping behaviours used. In Thompson et al.'s model, chronic illness is viewed as a potential stressor to which the individual and family systems must adapt (61). Similarly to other theorists, Thompson's model of transaction supports that child and maternal adaptation is based on their adjustment to the demands imposed by the chronic conditions.

This notion of transaction is supported by Falik et al. who maintain that the child, the parent and the environment are not independent from one another. The conceptual model derived from this study illustrates that the child's chronic condition or disease can impact family dynamics and consequently on the interactions between the parent and the child (62). Interactions can be positive, protective, functional or negative and can prohibit positive responses and adaptation (62). This last model incorporates Lazarus et al.'s choice of adaptive coping processes to reduce the impact of stress (50).

Although less easily applied to clinical research, McCubbin et al.'s T-Double ABCX model adds to the above-mentioned models by describing the variables involved in family pre-crisis adjustment and family post-crisis adaptation (45). To better apply this model to clinical practice, a process model called the Family Adjustment and Adaptation Response (FAAR) derived by McCubbin et al. (46). This model identifies the variables involved in the family system's

(individual, family and community) pre-crisis adjustment and post-crisis adaptation as a function of the accumulation of demands, appraisal of the stressful situation, family capabilities such as their coping behaviours and resources (family, social and healthcare related support) (45). This model may therefore be the most appropriate for understanding the effect of living with a child with a chronic condition on parental coping.

2.3.1 FAAR model

In this next section, the major components of the FAAR model are described. They include parental appraisal, adjustment/adaptation, parental coping and family, social and healthcare related resources, which are involved when the family is presented with a stressful situation.

2.3.1.1 Cognitive appraisal

Cognitive appraisal is described by Lazarus et al. as a process through which the person evaluates whether a particular event might impact the individual's well-being and, if so, in what way (50). Parents who have recently learnt of their child's chronic condition must evaluate the demands imposed by the stressor event on the family and use the family's various coping behaviours and associated resources (family related, socially related and healthcare related) to better their family situation. By appraising the situation, the parents are qualifying how stressful it is and how it may threaten the family's stability. Appraising is the action by which the family decides if they can overcome a stressor and is based on the family's characteristics (ethnicity, family dynamics, household income) (45).

Stress and coping theorists support cognitive appraisal as having a mediating effect in the parents' stress-response to their child's dysfunction (45;50). Findings from Lustig et al. on parents of children with juvenile rheumatoid arthritis showed that mother's appraisal of the impact of the situation on the family had a mediating effect on the association between a child's functional status and maternal mental health, where mother's positive appraisal of the situation corresponded to better maternal mental health and family adjustment (18).

2.3.1.2 Adjustment and adaptation

The family will rely on their different coping behaviours, as well as their associated family, social and healthcare related resources to adjust and limit the disruption of the family unit. These strengths and capabilities will help in resisting crisis and promote adjustment. However, if a crisis situation cannot be avoided, the family will utilize their capabilities to adapt to their stressful situation (45).

Once the initial appraisal of the situation is completed, the parent then needs to adjust to the new stressor. Adjustment has been defined as a short term response to expected day to day stressors and transitions (45). Family support, good marital situation, strong social support network, child adjustment and community service utilization together predicted 60% of the variance in maternal adjustment (60). For instance parents of children with juvenile rheumatoid arthritis (JRA) must adjust their family's life to accommodate the frequent medical visits, the multi-component treatment regimen (medication and/or home exercise

programs) and their child's sometimes unpredictable illness course (29). Although family adjustment is adequate in most family situations, there are situations where the demands brought forth by the stressor surpass the family's available resources (e.g. child newly diagnosed with a chronic condition) (45). Noojin et al. showed that mothers' perception of competence in problem solving was positively related to better adjustment (10). Others have found important associations between family adjustment and the chronic condition's characteristics (severity, functional status, and duration of disease), the child's characteristics relating to the child's coping behaviours and cognitive processes, the parent's adjustment and the family environment including socio-economic status (SES) and family dynamics (41).

Many have shown that parents who care for children with chronic illnesses experience varying levels of adjustment irrespective of the child's condition (16;17;47-49). When a state of imbalance persists, the family is pushed into a state of crisis.

Crisis is brought forth when the family's structure is altered, when the strengths and capabilities are being depleted due to ongoing stressors and unresolved strains (e.g. persisting marital conflict), when the family's capabilities or demands are underdeveloped and inadequate to meet the demands (e.g. limited income to care for the ill child). Crisis describes the amount of disruptiveness and disorganization within the family system (63). A state of family crisis is a transitional state in the family's attempt to overcome and adapt to changes internal

and external to the family unit in an effort to regain their initial level of family functioning (45).

Family adaptation follows a crisis situation. It differs from family adjustment as it is a long-term response to one of the family's ongoing stressful events. The adaptation phase is a function of the family's accumulation of demands on or in the family. It is a process by which the family utilizes their different resources and strengths over time to recover from a crisis situation. The process of acquiring and utilizing resources is essential to both the family's adaptation and adjustment response and it is known as coping (46). To respond to the increasing demands of their stressful family situation, parents must rely on different coping behaviours to ensure adjustment and adaptation (45).

2.3.1.3 Parental coping

According to Folkman et al., coping refers to the person's constantly changing cognitive and behavioural efforts to manage specific strenuous external and/or internal demands (64). When examining coping as a process: two functions are highlighted; problem-focused and emotion-focused coping (50;65). First, problem-focused coping involves dealing with the problem that is causing the distress by changing the stressful situation by adapting oneself or altering the environment. These are active responses, such as seeking information, seeking social support, preparing a plan of action with the purpose of mastering the situation. Second, emotion-focused coping involves regulating emotion such as

accepting it or holding back from acting impulsively. These are passive responses such as escape-avoidance, distancing, self-controlling and denial with the intention of reducing the stress level and/or changing the person's perception of the situation. The person will use a combination of coping behaviours to deal with the stressful situation in an attempt to limit emotional distress. Similarly, we expect that parents will choose specific coping responses when confronted with caring for their child with a chronic condition to help deal with their daily family demands.

More specifically, parental coping is described as a "specific effort by which the parent attempts to reduce or manage a demand on the family system" (45). These behaviours can be classified into patterns according to the different resources used (e.g. family, social and healthcare related resources) (59). Parental coping is considered an active process encompassing both the use of the existing family resources and the development of new behaviours and resources which may help strengthen the family and alleviate or reduce the impact of the stressful event at both the adjustment and adaptation phases (66). In addition to the resources available to the family, parental coping may also involve acquiring additional resources not already available to the family, such as finding the appropriate external social support, medical and rehabilitation services for a child diagnosed with a chronic condition.

2.3.1.4 Family related resources

Family resources refer to the broad range of family characteristics, which may be useful in times of need (67). These can be practical such as family income and maternal education or psychological such as cohesion, organisation and family mastery. Psychological family resources are defined as the way the family perceives and interacts with the social world internal and external to the family unit (67).

Family cohesion refers to the degree of commitment, help, and support family members provide to one another (37;45). Better family cohesion may be associated with greater social competence (22) and greater social integration in children with juvenile rheumatoid arthritis (37). Also, family cohesion allows for better family adjustment (22).

The way one masters a stressful situation relates to their ability to handle the stressors associated with the child's illness (37). Better maternal mastery was significantly associated to lower child's distressed mood (37). This resource in turn impacts upon the family's adaptability, which refers to the family's capacity to meet obstacles and shift its course of action to a more appropriate one (45).

Family organisation is another resource that families can rely on. In fact, a family that is disorganised is known not to react as efficiently as one who is organised (22). This family resource has been significantly associated to the

chronically ill child's level of adjustment (22), where better family organisation and higher maternal education was associated to better child psychological adjustment (22). Also, acquiring community resources can be influenced by severity of the child's condition, where parents of children with more severe juvenile rheumatic disease showed greater ability in organising the family to obtain help community resources than did families of less affected children (56).

The family's practical resources, such as maternal education and family income, were both significantly associated to better child adjustment in children with various chronic conditions (juvenile diabetes, juvenile rheumatoid arthritis, chronic obesity, spina bifida, and cerebral palsy) (22). In this same study, the family's psychological resources, such as cohesion and organisation, were found to be significantly associated to better child's psychological adjustment (22).

2.3.1.5 Social related resources

McCubbin et al. have suggested that social support has a mediating effect on parent's stress-response process (45). Social support refers to an exchange of resources between at least two individuals with the intent of helping the person in need (68), through provision of emotional and community support (69). In our study, the recipient is the family and the providers can either be external family members, friends, neighbours or even community professionals. Mothers of children with spina bifida, who have a large social network composed of friends and family members who provide psychological and material resources, have

shown better adjustment (70). The better surrounded the family is by a social network, the better the outlook. This in turn helps the family's strengthen its perception of stability (71). However, these relationships also have demands and strains felt within the relationship and can only be helpful if the interactions have an overall positive effect (50).

Social support may improve well-being for persons under stress. Findings from Sallfors et al. on parental perspective regarding living with a chronically ill child support the alleviating properties of social support when coping with their stressful family situation (72). Social support is most effective when it matches the particular stress being experienced (71) and has been found to be positively associated to greater family strength and empowerment (4). Also, social support under the form of respite care may reduce parental stress in families with developmentally disabled children (73).

Among the parents caring for children with disabilities, 20% reported that they received help with housework (housecleaning and meal preparation), family responsibilities, and time off for personal activities because of their child's condition (25). Of these parents, 44% received help from family members not living with them and 27% from friends or neighbours (respondents could report more than one source of help) (25). These support the importance of the help provided to parents by informal sources of social support, i.e. actual assistance in every day life.

In addition to social support provided by friends and family members, help provided through formal sources, such as community services and/or government organizations, was used by 44% of Canadian parents who had children with a physical disability (74). Rimmerman et al. showed that parents of children with developmental disabilities who used respite care during an 18 month study reported reduced levels of stress and better coping in comparison to higher levels of stress for families that did not use respite care (75).

2.3.1.6 Healthcare related resources

Resources provided by healthcare and medical professionals can encompass information concerning their child's chronic condition such as prognosis, medication and other possible interventions, referrals to other relevant services and formal emotional and psychological support. Parents of children with juvenile chronic arthritis have reported that support from healthcare professionals is important to them (72). Poor support, limited information and services, as well as poor communication between parents and healthcare professionals heightened levels of uncertainty and anxiety amongst these parents (72). In some cases, waiting lists for rehabilitation services within the public system are exceedingly long, and parents must either cope with the lack of services or pay for costly private services (76). Barlow et al. found that inadequate support from healthcare professionals and lack of information prevented parents of children with juvenile chronic arthritis from coping with their child's condition (77). Furthermore,

parents purport that professionals, who take the time to explain and review things with them were most appreciated (72).

Heiman et al. found that 93.5 % of parents caring for a child with either an intellectual, physical or learning disability used psychological services either for the ill child, for themselves or for the siblings to provide them with guidance and emotional support (53). Furthermore, children with physical disabilities who used more educational and medical services had mothers who displayed better social function (60). When parents are unable to acquire such support, it is important that healthcare professionals be present to guide them through this difficult time and inform them on the different services available in order to encourage family empowerment and the use of different adaptive coping behaviours (78).

In summary, families often adapt differently to stressful events (9;66) and will not utilize the same coping behaviours. McCubbin et al. hypothesized that families possessing a larger range of coping behaviours will manage the situation of caring for the chronically ill child more effectively (45). These coping behaviours refer to the family's actions to maintain the emotional stability and well-being of family members. This can be accomplished by obtaining and utilizing family (internal and/or external to the family unit) and community resources (e.g. healthcare professionals involved in their child's health, community based services) to manage the situation and attempt to resolve the family hardships caused by the stressor event or transition. Parents can seek out information

sources such as healthcare professionals to gain knowledge of their child's condition, prognosis and intervention regimen. The family can also maintain these social resources in an attempt to develop a network available for further crisis situations. Although the literature is very extensive in illustrating the factors that impact parental adjustment, distress and stress, little is known about what impacts the choice of parental coping behaviours. The coping behaviours described in the next section are taken from different parental coping measures, which use differing terminology.

2.4 Factors associated with parental coping

Over the years, only a handful of studies have explored the different characteristics of the child, the parent and the family that may impact parental coping. The child's characteristics (e.g. age and gender, severity of the condition and disease duration), the parent's characteristics (e.g. age, level of education, working status, civil status) and the family environment characteristics (e.g. family dynamics, ethnicity, household income) are inter-related and may impact upon use of parental coping behaviours (62).

2.4.1 Child related characteristics

Age of the child may influence parental coping. Judge (1998) found that parents of older children revert to a Wishful Thinking coping behaviour (behavioural efforts to escape or avoid the problem) as measured by the Ways of

Coping Questionnaire (WCQ) (4). These findings are supported in part by Tak et al., who showed that although maternal coping was not related to age, paternal coping was, where fathers of older children with a diagnosis of congenital heart disease used more coping behaviours (6). On the other hand, Ellis et al. showed that younger children with developmental disabilities posed greater demands on their parents, explaining that the parent of a younger child is inexperienced and is not used to dealing with the services available to the family (1). Although, the author attempts to support her results she also agrees that the opposite findings are easily justified by the fact that caring for an older child is more demanding on the parent, therefore requires more social support and possible long-term placement. Her study sample was composed of children aged three to twenty-two years of age.

Only a few studies examined the influence of severity of the child's condition on parental coping (6;79). Tak et al. showed no significant association between parental coping behaviours measured by the Coping Health Inventory for Parents (CHIP) and severity of the child's congenital heart disease (6). They concluded that parents may cope differently irrespective of disease severity; some families adapt better than others when faced with similar stressors. Interestingly, a study completed by Patterson et al. showed that an improvement in pulmonary function, in the child with cystic fibrosis, was significantly associated with the use of parental coping behaviours related to Maintaining Social Support from the CHIP (79).

Other factors such as gender and disease duration were not found to be associated with parental coping in children with type 1 diabetes (80).

2.4.2 Parent and family environment related characteristics

Parent's age, socioeconomic status and personal characteristics have shown to significantly impact the use of parental coping.

Younger mothers were more inclined to rely on Wishful Thinking (behavioural efforts to escape or avoid the problem) or Self-Blame (acknowledgement of one's own role in the problem and efforts to put things right) coping behaviours when caring for a child with a disability receiving an early intervention program or those at-risk for developmental delays (4). Also, younger mothers of children with congenital heart disease tend to want to Maintain Family Integration, cooperation, and an optimistic definition of the situation and Understand the Medical Situation through communication with other parents and consultation with the medical staff (6). On the other hand, older mothers caring for a child with Down syndrome tended to adopt a stoïc approach which involves making light of the situation or refusing to get too serious about it (81). Younger fathers relied more on the coping pattern related to Maintaining Social Support when caring for their child with congenital heart disease (6).

Socio-economic status (SES) and associated factors also impact parental coping. The studies completed by Judge and Knussen et al. showed negative

correlations existing between socio-economic status (SES) and the choice of coping behaviours, when caring for a child with a disability (4;81). Judge found that families of lower SES had parents that were inclined to adopt behaviours related to Self-Blame and Wishful Thinking (4). Similarly, Knussen et al. found that parents completing manual work (i.e. lower SES) were more likely to have higher scores on the Wishful Thinking subscale (81). In addition a lower level of maternal education as a proxy for lower socioeconomic status showed that Self-Blame and Wishful Thinking were mostly used (4).

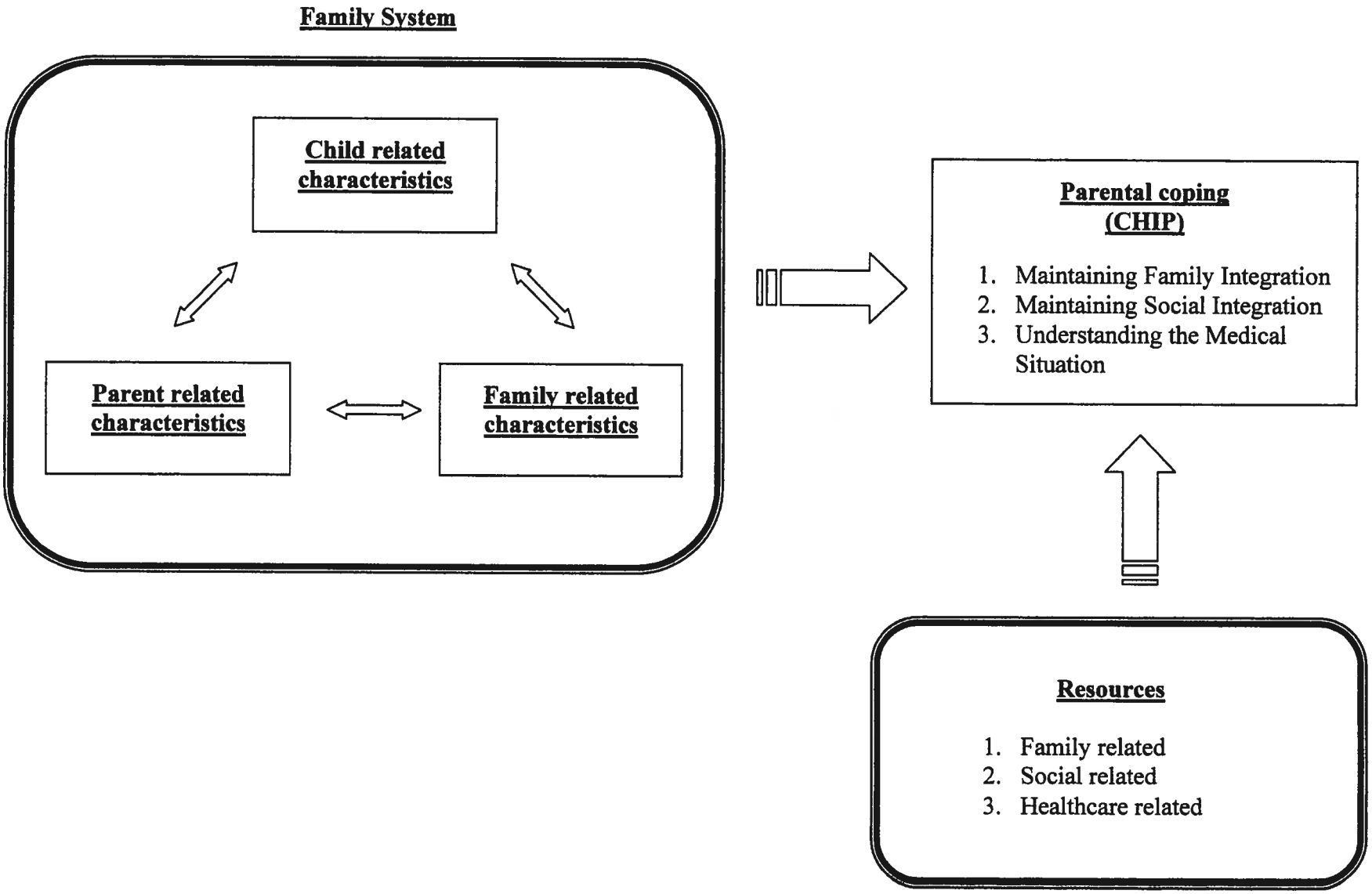
The effects of a parent's skills, such as the ability to master the stressful family situation, to problem solve and to organise their schedule are examined. The better the father masters the stressful situation, the greater the attempt to maintain a positive view of the stressful situation when caring for their child with juvenile rheumatoid arthritis (JRA) (15). Greater confidence in one's problem-solving abilities amongst mothers caring for children with physical disabilities (e.g. spina bifida and cerebral palsy) was associated with the use of more approach type coping behaviours (problem-solving and seeking social support) rather than avoidance types (10). Conversely, mothers who felt less in control in remedying their situation relied mostly on avoidance type coping such as Wishful Thinking, Avoidance and Self-Blame behaviours (10). Avoidance coping behaviours are considered maladaptive because of the high association with greater maternal psychological distress (10). The qualitative findings advanced by Valentine explain that parents who are required to bring their children to multiple

appointments, frequently are unable to manage their schedule and have difficulty coping with the demands of caring for their child (7). Thus, it would seem that the frequency of services received coupled with the parent's inability to manage their situation may influence parental coping.

There appears to be no significant correlation between parent's gender or marital status and their use of parental coping behaviours (81).

Given the literature and existing models, we have organized factors under study in a conceptual framework (Figure 1). The figure illustrates the family system, which includes the child's characteristics (age, gender) and disease related characteristics (functional status, diagnosis, rehabilitation and/or medical services received), the parent's characteristics (employment status, gender, age, level of education) and the family environment characteristics (household income, family structure (1 or 2 parents), family dynamics). It is important to note that the family system's factors may also be associated with one another, as well as parental coping as proposed by the Coping Health Inventory for Parents (CHIP). In addition resources can be classified under family related (SES, family structure), social related (respite care, support groups) and healthcare related (medical or rehabilitation services available). The availability of the existing resources may also have been associated with parental coping.

Figure 1: Illustration of the family system (i.e. characteristics related to the child, the parent and the family environment) and related resources (family, social and healthcare) and the association with parental coping in children with chronic conditions such as JIA and PD.



CHAPTER 3 - METHODS

3.1 Participants

The first cohort was composed of parents, either the mother or the father, caring for a child with JIA (n=182) who attended the JIA clinic at two Canadian pediatric hospitals (Montreal Children's Hospital-McGill University Health Centre and British Columbia's Children's Hospital in Vancouver) from September 2000 to January 2004 and were following active treatment at the out-patient JIA clinic. Parents were eligible for the study if they spoke and understood either English or French and if their child was undergoing treatment with medications and an exercise program.

The second cohort, was composed of parents, either the mother or the father, caring for a child with physical disabilities (PD) referred to pediatric rehabilitation centres but still waiting for services in OT and/or PT, in the Montreal region, from one of two pediatric tertiary care teaching hospitals, the Montreal Children's Hospital (MCH)-McGill University Health Centre and the Hôpital Sainte-Justine's (HSJ)-Centre Hospitalier Université de Montréal (n=150). Families resided in Montreal and surrounding areas (50-km radius). Children with a disability due exclusively to a cognitive delay were excluded. The study took place between August 2002 and March 2004. Parents were eligible for the study if they spoke and understood either English or French.

3.2 Data Collection

Data analysed as part of this master's project were collected for two cohorts of parents participating in separate studies on JIA and PD. The first cohort (JIA) participated in a study exploring adherence to treatment while the second cohort (PD) participated in a study assessing waiting times and related factors for pediatric rehabilitation services in preschool-aged children.

Parents of children with JIA were approached during the time their child attended the JIA out-patient clinic and were asked to complete the following questionnaires and to return them by mail: 1) the CopingHealth Inventory for Parents (CHIP), 2) the Juvenile Arthritis Quality of life Questionnaire (JAQQ), 3) the Symptom Checklist-90-Revised (SCL-90-R), 4) Child Health Questionnaire–Parents Form-50 (CHQ-PF-50), 5) Socio-demographic questionnaire which included information on parents' education, socio-economic status (SES), and ethnicity. Data were collected at three time points: entry into the study (baseline), six months (T6) and 12 months (T12) later. In order to increase our sample power we included data from all three time intervals. This study was approved by the Montreal Children's Hospital and the British Columbia's Children's Hospital Institutional Review Boards.

Parents of children with PD were recruited and completed the following series of questionnaires through face to face interview: 1) the Coping Health Inventory for Parents (CHIP), 2) the Functional Independence Measure for

Children (WeeFIM), 3) the Family Empowerment Scale (FES) and 4) Socio-demographic questionnaire. Data were collected at three month intervals until the child received the requested services. For the purpose of the present study, we have concentrated on baseline results. The reason for this is that there was a recognisable pattern of children leaving the cohort based on their acceptance to rehabilitation centres (e.g. younger children and those with specific diagnoses), which limits our sample size and power. The study protocols were approved by each of the two hospital's research ethics committees. Written parental informed consent was also obtained for all participants. This study was approved by the Montreal Children's Hospital and the Sainte-Justine Hospital Institutional Review Boards.

3.3 Measures

Several tools were used in this study. Some were used for both cohorts while others were specific to each cohort. In either case questionnaires were available in French and English to accommodate Quebec's two official languages. They were chosen for their ease of administration and the quality of their psychometric properties.

Socio-demographic characteristics were collected using a questionnaire developed specifically for the study on children with JIA (Appendix III). It included questions about the parent's age, level of education and work status;

family's ethnic background and household income. Similarly a questionnaire was also developed for the cohort with children with physical disabilities (Appendix IV), which consisted of questions regarding district of residence, mother's educational level, family income, and receipt of rehabilitation services (PT and/or OT) including public and private sources. All other information regarding the child and condition was abstracted from the medical chart in both cohorts.

For both cohorts parental coping was measured using the *Coping Health Inventory for Parents (CHIP)* (82). The CHIP was first developed to assess parental coping patterns in parents of children with cystic fibrosis (82). This questionnaire was based on the conceptual framework provided by Hill's ABCX model and McCubbin's Double ABCX model. This highlights coping as a process, which changes with the situation (83).

The questionnaire has 45-items and is a valid and reliable measure by which parents indicate the type of coping behaviours they use in response to their child's illness. Parents rate their perceptions of how useful these behaviours are by using a four-point Likert scale from not helpful [0] to extremely helpful [3]. There are three main subscales of coping patterns formed by the sum of specific related items. The first coping pattern is *Maintaining family integration, cooperation, and an optimistic definition of the situation* (19 items, maximum score =57), which refers to, for example parents participating in activities with other family members or getting other family members to help with chores and

tasks at home. The second coping pattern is *Maintaining social support, self esteem, and psychological stability* (18 items, maximum score = 54), which refers to, for example parents getting away from the home care tasks and responsibilities for some relief or talking to someone about how they feel. The third coping pattern is *Understanding the medical situation through communication with other parents and consultation with the medical staff* (8 items, maximum score = 24), which refers to, for example parents talking with the medical staff (nurses, social worker, etc.) when visiting the medical centre or with the treating physician. Higher scores for each subscale indicate more usefulness for that particular type of coping pattern. For the purpose of this study, we derived what we have coined the percentage maximum score for each pattern to allow for better comparison of coping results across the study period. For the purpose of this study, we have calculated the percentage of the maximum score per pattern to allow for comparison across the study period. This percentage was calculated by dividing the total score for each coping pattern by the maximal possible score of that specific pattern. The internal consistency is good with Cronbach alphas of 0.79; 0.79; 0.71 for each subscale, respectively (82). The CHIP has fair concurrent validity with several correlations with the Family Environment Scales (45). The test retest reliability of the German version is 0.75, 0.63 and 0.57 respectively for the three subscales and construct validity has been supported by correlations between it and the Trier scale, a multidimensional coping questionnaire for adult patients (84).

3.3.1 Measures for the JIA cohort

The following four measurement tools were used with the JIA cohort. The *Juvenile Arthritis Quality of life Questionnaire (JAQQ)* (Appendix VI) was developed to measure disease-specific quality of life in children with JIA (85;86). In addition to being a measure of HRQL, Brunner et al. found that the JAQQ is significantly correlated to the Childhood Health Assessment Questionnaire (CHAQ), which is a measure of function (87). The JAQQ has 4 subscales: 1) gross motor function (17 items), 2) fine motor function (16 items), 3) psychosocial function (22 items), 4) systemic symptoms (19 items) and a section assessing pain, using a 100 mm visual analogue scale, which is not included in the total score. Each domain is scored using a seven-point Likert scale from none of the time [1] to all of the time [7], where higher scores correspond to a greater level of dysfunction when completing tasks as a result of arthritis or its treatment within the two past weeks. A score of zero is attributed if the item is not developmentally appropriate for the child to complete. A mean score for the highest five items of each subscale is computed, hence four subscale scores are computed at one time. The total JAQQ score is obtained by computing the mean of the four subscales mean scores (86). Content validity is supported by the correlations between the different subscales of the JAQQ and measures of joint disease activity and pain, ranging from r=0.32 to r=0.49 (86). Good correlations were found between all the JAQQ subscales, pain and the physician's global evaluation of change, demonstrating that the JAQQ is responsive to important change in child's functional status (86;88). Internal consistency was not reported. Test-retest

reliability is not measured for this tool, because it was constructed to measure functional change in each individual being assessed.

Although children nine years and older can complete the questionnaire, we used only the parent's report of their child's HRQL to ensure greater consistency across subjects. The parent answers all questions once and then chooses a maximum of five tasks reporting the highest levels of dysfunction for the child. Quality of life measures are often based on both health status and functional status (86). In light of the fact that this questionnaire assesses the child's level of function for each subscale, we purport that it would be adequate as a measure of disease severity for our JIA cohort. This tool was used to obtain a measure of quality of functional severity.

The *System Checklist-90-Revised (SCL-90-R)* (Appendix VII) evaluates an array of psychological problems and symptoms of psychopathology of the parent (89). This instrument is composed of 90 items using a five-point rating scale of distress ranging from "not at all" [0] to "extremely" [4]. This tool measures nine primary symptom dimensions and three global indices of functioning (i.e. Global Severity Index (GSI), Positive Symptom Distress (PSD), and Positive Symptom Total (PST)). For our study, we focused solely on the GSI, which measures overall psychological distress. We used Derogatis' measure of 'caseness' where a t-score equal to or greater than 63 is indicative of parental psychological distress (88). The SCL-90-R demonstrates adequate internal scale consistency from 0.77

to 0.90 and reasonably good test-retest reliability (1 week) from 0.78 to 0.90 (89). The validity of the six subscales was confirmed by the finding of significant relationships with the associated DSM-IIIR/DSM-IV symptom disorders (90).

The *Child Health Questionnaire-Parent Form-50 (CHQ-PF-50)* (Appendix VIII) measures health-related quality of life from the parent's perspective (91;92). This is a self-administered questionnaire of 50 items, which covers areas such as child's global health, performance in physical and everyday activities, pain level, behaviour, well-being, self-esteem and the relation between family members. In our study, information regarding family dynamics was obtained by asking parents to rate how well their family gets along using a scale from excellent [1] to poor [5]. Item and scale internal consistency and item discriminant validity were found to be good to excellent, and construct validity was supported (93).

3.3.2 Measures for the PD cohort

For the PD cohort the following measures were used. The *Functional Independence Measure for Children (WeeFIM)* (Appendix IX) is a pediatric functional assessment adapted from the Functional Independence Measure designed to measure disability in adults (94). The WeeFIM evaluates various disabilities and measures functional status in children with disabilities aged from six months to 12 years of age (95). The WeeFIM is versatile in that it assesses disability (degree of performance of tasks) in performing self-care, mobility and cognition related tasks (95). It has been used with different populations of

children with developmental disabilities (e.g. Down Syndrome, limb deficiency, motor impairments, spina bifida, prematurity, cerebral palsy, developmental delays) (96). This tool contains 18 items divided over six subscales: Self-care, Sphincter control, Transfers, Locomotion, Communication, and Social Cognition. These are further grouped into three distinct domains: Self-care, Mobility and Cognition. Each subscale consists of two to six items that are scored separately. An ordinal rating system ranging from complete independence [7] to total assistance [1] is used. A rating of 7 to 6 means that the child can complete the activity independently but may require an assistive device, need more time than expected, or need assistance if worries of safety exist. A rating from 5 to 3 indicates the need for modified dependence; either supervision or a degree of personal assistance to complete the task. A rating from 2 to 1 indicates complete dependence; a score of 2 indicates maximal assistance (child needs help from adult to complete the majority of the task); a score of 1 is given when the caregiver performs the whole task for the child. No zero or non-applicable ratings can be given (96). The minimum possible rating is 18 (total dependence in all skills) and the maximum is 126 (complete independence in all skills) (96). Scoring consists of calculating quotients for the three subscales (self-care, mobility, cognition) and for the total score, with lower quotients representing higher levels of disability. The child's developmental functional quotient is calculated by the percentage of the total score over the maximal score, whereas the functional independence score is calculated by the percentage of the total score by the mean score for age (97). A quotient of 75 or higher represents a mild disability, a quotient of 50 to 75

represents a moderate disability and that below 50 represents a severe disability (98).

Test-retest reliability is high for the three domains and total score; ranging from 0.89 to 0.99 (97). The inter-rater reliability is also appropriate ranging from 0.87 to 0.95 for all domains and total WeeFIM (97). Criterion-validity is supported by Pearson correlations of the different WeeFIM scores and the extra help and time needed by the child to complete a certain activity in comparison to the norm (97). These correlations are as follows: 0.81/0.71 for self-care, 0.77/0.41 for mobility, 0.96/0.73 for cognition and 0.95/0.88 for total WeeFIM between (97). We administered the WeeFIM through parent interview. An intraclass correlation coefficient (ICC) of 0.93 supports consistency between the two modes of administration parent interview and direct observation (96).

The *Family empowerment scale (FES)* (Appendix X) is a questionnaire measuring the level of empowerment as well as the way that empowerment is expressed (99). The entire test consists of a 34 item self-report scale that accounts for the three following dimensions of empowerment: 1) family, which relates to the parents' efforts to manage the everyday demands, 2) service system, which refers to the parent and the service system working together to get the services the child needs, and 3) community/political, where the parent is an advocate for advancements and changes in the service delivery for children in general. Three

modalities are examined for expressing empowerment (attitudes, knowledge, and behaviours). In our study, parents completed the service system dimension (12 items) of this scale which refers to empowerment in relation to the service system. It explores parent's relationship with healthcare professionals involved in their child's care and the level of comfort in asking questions and voicing their opinions. The parent's empowerment regarding service system is assessed by using a five-point Likert scale from not true at all [1] to completely true [5]. A summary score is generated for this dimension.

The internal consistency (Cronbach alpha) of the service system dimension was 0.87 and the test-retest reliability was 0.77. Several validity studies were conducted for the test as a whole but not on the service delivery dimension itself.

3.4 Analysis

Univariate analyses were completed to describe baseline characteristics of the sample and to examine distributions of different variables for the JIA and PD cohorts.

Separate analyses were conducted with data for each cohort. All analyses were performed using SPSS software version 14 (Chicago, Il) (100).

In the JIA cohort to enhance the sample power we took advantage of the repetitive measure aspect of the study and included all time intervals in our analysis. For the JIA cohort the characteristics of participants and non-participants were compared at baseline, 6 and 12 months later using either a chi-squares or a t-test to analyse the differences. Mean and standard deviation of coping patterns were then calculated at the three time periods. Multivariate analyses using Linear Mixed Models were conducted to determine associations between functional severity of the child's illness and 1) parental coping pattern and 2) parental psychological distress, adjusting for age, gender, disease duration, pain level, maternal education (no education beyond high school versus post-secondary education), maternal employment status (working or not), family structure (one or two parent), family dynamics (excellent to very good, good or fair to poor), household income (<35,000 $, 35,000-64,999 $ or ≥65,000 $) and ethnicity (French Canadian, English Canadian or Other). We used two models for each of the above: in the first model total JAQQ score was the main independent variable representing functional severity, while in the second model four subscales of the JAQQ were the main independent variables. In our analysis, we used the Linear Mixed Model approach which is a generalization of the standard linear model that allows combination of the same subjects' data over the study period in one analysis. Furthermore, we used residual maximum likelihood as the method of parameter estimation with compound symmetry as the covariance structure based on Schwarz's Bayesian Information Criterion (101). All variables were treated as

fixed-effect parameters except for the intercept which was treated as a random-effect parameter.

Our initial models included all variables mentioned above. In a second run, variables with a p-value>0.2 were dropped. Then model selection was continued until all variables in the model attained a p-value<0.05. However, the main independent variable (Total JAQQ score or its four subscales) as well as age and sex variables were always forced in the models irrespective of their significance value. Final model selection was based on the above criteria. To enhance comparability across the three models of family coping variables, we re-introduced all significant variables in either of three models into all our final models.

For the PD cohort the characteristics of participants and non-participants were compared at baseline using either a chi-square or a t-test to analyse the differences. Mean and standard deviation of coping patterns were also calculated at baseline. With respect to the PD cohort multiple regression analysis determined the associations between severity of the child's condition (WeeFIM) and parental coping adjusted for variables based on the literature and those of interest such as: child's age, gender, diagnostic group (global developmental delay versus specific diagnosis), OT and/or PT services received, maternal level of education (no education beyond high school versus post-secondary education), parent's employment status (working versus not working), family structure (one or two-parent), household income (≤$39,999, $40,000-59,999 or ≥$60,000), and ethnicity

(French Canadian, English Canadian or other). For both models the dependent variables were the three subscales of the CHIP. In the first model, the total WeeFIM score was the main independent variable, while in the second model the scores for the three WeeFIM subscales were the main independent variables. Multiple linear regression models were also used to determine whether total functional severity score as well as its three domains were associated with parental empowerment (service system subscale).

Similarly to the JIA cohort our initial models for the PD cohort included all relevant variables mentioned above. After a second run, variables with a p-value>0.2 were dropped and model selection was then pursued until all variables in the model attained a p-value<0.05. However, the main independent variable (Total WeeFIM score or its three subscales) as well as age, sex and diagnosis variables were always forced in the models regardless of their significance value. Once again final model selection was based on the above criteria and comparability was favoured across the three models of family coping variables by re-introducing all significant variables in each of the three models into all final models.

CHAPTER 4-ARTICLES

The results of this analysis are presented in the following articles, which have not yet been submitted for publishing:

Article 4.1: Is Parental Coping Associated with Functional Severity in Juvenile Idiopathic Arthritis?

Sabrina Cavallo, Debbie Ehrmann Feldman, Bonnie Swaine, Garbis Meshefedjian, Peter N Malleson, Ciarán M Duffy,

Article 4.2: Is Parental Coping Associated with Functional Severity in Children with Physical Disabilities?

Sabrina Cavallo, Debbie Ehrmann Feldman, Bonnie Swaine, Garbis Meshefedjian

Article 4.1: Is Parental Coping Associated with Functional Severity in Juvenile Idiopathic Arthritis?

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4.1.1 Abstract

OBJECTIVES: 1) To describe parental coping patterns in a cohort of children with JIA; 2) to determine whether disease severity is associated with parental coping; 3) to explore whether socio-demographic factors such as child's age, maternal education and family structure are associated with parental coping patterns.

METHODS: Parents (mother or father) of children with JIA completed a postal survey three times over a one-year period including the Coping Health Inventory for Parents (CHIP), the Juvenile Arthritis Quality of Life Questionnaire (JAQQ) and questionnaires describing socio-demographic characteristics. Analysis consisted of a description of three coping patterns (CHIP subscales) at each assessment time and determining the association between disease severity and other factors with parental coping patterns used.

RESULTS: One hundred eighty-two parents caring for a child with JIA (mean age of 10.2 ± 4.4 years, 69.2% female) participated. Mean parental coping scores for the CHIP subscales at baseline were 38.4±9.0, 33.4±11.6, 16.5±6.1, for Maintaining Family Integration (maximum score 57), Maintaining Social Support (maximum score 54) and Understanding the Medical Situation (maximum score 24), respectively. Understanding the Medical Situation was deemed most useful. Parents of children with greater psychosocial dysfunction used more coping behaviours related to Understanding the Medical Situation (β coefficient, 0.73; 95% CI, 0.01, 1.45). Greater use of certain coping behaviours was associated with lower maternal education, better family dynamics and English Canadian ethnic background.

CONCLUSION: Understanding the Medical Situation was considered the most useful coping pattern among parents in our study. These findings underscore the importance of helping parents of children with JIA better understand the medical situation.

4.1.2 Introduction

Juvenile idiopathic arthritis (JIA) is a heterogeneous group of conditions characterized by inflammation of the connective tissues (e.g., the joints) (1). According to Page it is the fifth most chronic disease in children (2). Children affected by JIA report chronic pain, stiffness in joints, fatigue, limitations in mobility which may limit their participation in daily activities and possibly lead to permanent disability and deformity (3;4). These limitations may in turn affect parents' well-being.

Parents of children with chronic medical conditions such as (JIA) must cope with greater demands when caring for their children in comparison to those with healthy children (5). Furthermore, these parents are at greater risk of becoming psychologically distressed (6). They must adjust their family life to accommodate the frequent medical visits, the multi-component treatment regimen and their child's unpredictable illness course (7;8). Mothers of children with chronic medical conditions display lower levels of physical functioning versus those with healthy children (5). Furthermore, maternal depression appears to be positively correlated to the child's level of disability (9).

Parental coping refers to a specific effort by which the parent attempts to reduce or manage a demand on the family system (10). According to Folkman et al., coping is defined as the person's constantly changing cognitive and behavioural efforts to manage specific taxing external and/or internal demands

(11). The latter definition considers two processes, cognitive appraisal and coping, as the two main mediators of stressful person-environment relationships and their immediate and long-term outcomes (11). In this article, we examine only parental coping. Although many studies report associations between parental stress level and living with a chronically ill child (12-16), few explore the impact of functional severity of the child's disease on the use of parental coping behaviours. Moreover, the results have been conflicting.

Tak et al. showed no significant association between parental coping behaviours measured by the Coping Health Inventory for Parents (CHIP) and severity of the child's congenital heart disease (15). They concluded that, parents may cope differently irrespective of disease severity; accordingly, some families adapt better than others when faced with similar stressors. Interestingly, a study completed by Patterson et al. showed that an improvement in pulmonary function in the child with cystic fibrosis was significantly associated with the use of parental coping behaviours related to communicating with the medical staff (17). Daltroy et al. showed that maternal mood was more negatively influenced for those living with a child with juvenile arthritis who was mildly affected compared to those living with a child who was unaffected or moderately to significantly affected (18). These results suggest a non-linear relationship between maternal mood and severity of the child's medical condition. Child functional severity, or the ability to complete age-appropriate social and physical activities (19-21), may

also have an indirect effect on maternal mental health (16) and consequently on the choice of parental coping.

The family stress theorists support the notion that adaptation to major life changes are in part influenced by family type and family strengths and capabilities (22). Thus, parental adaptation to living with a child with a chronic disease such as JIA may be predicted by different characteristics related to the child, the parent and the environment. These characteristics are mediated by parental appraisal of the situation and coping and resolved by the available social and personal resources.

The main stressor examined in this study is living with a child with JIA. We investigated characteristics that may influence parental assessment of the stressful event and utilization of cultural and social resources. These included characteristics related to the child (functional severity, pain, disease duration, age, and sex), those related to the parent (mother's age, level of maternal education, parent's employment status) and those related to the family environment (household income, family dynamics, structure and ethnicity). Accordingly, parents may rely on different coping behaviours to answer their needs. In turn, the preferred coping patterns may influence the child's functional status, parent's level of psychological distress, and family dynamics. We further purport that parental perception of disease severity may influence parental coping patterns.

The aims of this study were 1) to describe parental coping behaviours in a cohort of children with JIA, 2) to determine whether disease severity is associated with parental coping patterns, and 3) to explore what socio-demographic factors are associated with parental coping patterns. As an additional objective, we examined whether disease severity and socio-demographic factors are associated with parental distress. By identifying coping behaviours and the usefulness that parents attribute to them, we can guide parents in finding appropriate services for respite and emotional support in an attempt to provide quality care for their child with JIA, as well as their family.

4.1.3 Patients and methods

4.1.3.1 Participants

Parents, either the mother or the father, caring for a child with JIA (n=235) who attended the JIA clinic at two Canadian pediatric hospitals (Montreal Children's Hospital-McGill University Health Centre, n=144 and British Columbia's Children's Hospital in Vancouver, n=91) agreed to participate. Parents were eligible for the study if they spoke and understood either English or French.

4.1.3.2 Data Collection

This study was a secondary analysis of data collected as part of a larger study examining adherence to treatment for children with JIA. Parents of children with JIA were asked to complete the following questionnaires and to return them

by mail: 1) the Coping Health Inventory for Parents (CHIP), 2) the Juvenile Arthritis Quality of Life Questionnaire (JAQQ), 3) the Symptom Checklist-90-Revised (SCL-90-R), 4) the Child Health Questionnaire –Parent Form-50 (CHQ-PF-50), 5) a socio-demographic questionnaire including information on mother's education, socio-economic status (SES), and family ethnic background. Data were collected at three time points through self-report questionnaires during an out-patient JIA clinic: entry into the study (baseline), six months and twelve months later.

The study was approved by the Montreal Children's Hospital and the British Columbia's Children's Hospital Institutional Review Boards.

4.1.3.3 Measures

The Coping Health Inventory for Parents (CHIP) was used to measure parental coping patterns (23). This 45-item questionnaire is a valid and reliable measure by which parents indicate the type of coping behaviours they use in response to their child's illness. Parents rate their perceptions of how useful these behaviours are by using a four-point Likert scale from not helpful [0] to extremely helpful [3]. This questionnaire is composed of three main coping patterns. The first coping pattern is *Maintaining family integration, cooperation, and an optimistic definition of the situation* (19 items, maximum score =57), which refers to, for example parents participating in activities with other family members or getting other family members to help with chores and tasks at home. The second

coping pattern is *Maintaining social support, self esteem, and psychological stability* (18 items, maximum score = 54), which refers to, for example parents getting away from the home care tasks and responsibilities for some relief or talking to someone about how they feel. The third coping pattern is *Understanding the medical situation through communication with other parents and consultation with the medical staff* (8 items, maximum score = 24), which refers to, for example parents talking with the medical staff (nurses, social worker, etc.) when visiting the medical centre or with the treating physician. The higher the score the more useful the particular type of coping pattern. For the purpose of this study, we derived what we have coined the percentage maximum score for each pattern to allow for better comparison of coping results across the study period. This percentage was calculated by dividing the total score for each coping pattern by the maximal possible score of that specific pattern. The internal consistency of this tool is good with Cronbach alphas of 0.79; 0.79; 0.71 for each pattern, respectively (23). The CHIP has fair concurrent validity and correlates with the Family Empowerment Scales (23). The test-retest reliability of the German version is 0.75, 0.63 and 0.57; respectively for the three patterns and construct validity has been supported by correlations between it and the Trier scale, a multidimensional coping questionnaire for adult patients (24).

While other measures to assess disease activity and severity of rheumatic conditions (active joint count (AJC), erythrocyte sedimentation rate (ESR), patient/parent and physician global assessments) were used in our main study

these were not included in our present analysis. Here, we chose the Juvenile Arthritis Quality of life Questionnaire (JAQQ), a valid and responsive tool which measures disease-specific quality of life as well as function in children with JIA (25-27). This questionnaire has four domains: (1) gross motor function (17 items), (2) fine motor function (16 items), (3) psychosocial function (22 items), (4) systemic symptoms (19 items) and a section, not included in the total score assessing pain using a 100 mm visual analogue scale. Each domain is scored using a seven-point Likert scale from never [1] to always [7] and a zero score if the item is not applicable to the child; higher scores correspond to a greater level of dysfunction due to arthritis or its treatment within the past two weeks.

The System Checklist-90-Revised (SCL-90-R) was used to evaluate an array of psychological problems and symptoms of psychopathology in parents (28;29). This instrument is composed of 90 items measured using a five-point rating scale of distress ranging from not at all [0] to extremely [4]. This tool can measure nine primary symptom dimensions and three global indices of functioning (i.e. Global Severity Index (GSI), Positive Symptom Distress (PSD), and Positive Symptom Total (PST)). For the scope of our study, we focused on the GSI, which measures parents' overall psychological distress. We used Derogatis' measure of "caseness" where a GSI t-score equal to or greater than 63 is indicative of clinical psychological distress (29). The SCL-90-R demonstrates adequate internal scale consistency from 0.77 to 0.90 and reasonably good test-retest reliability (one week) from 0.78 to 0.90 (29). Validity of the SCL90R was supported by

significant associations with the corresponding DSM-IIIR/DSM-IV symptom disorders (30).

The Child Health Questionnaire-Parent Form-50 (CHQ-PF-50) is a valid and reliable tool that measures health-related quality of life from the parent's perspective (31;32). We used one item from the CHQ-PF-50 that provides information on family dynamics: how well their family gets along – rated on a scale from excellent [1] to poor [5].

Socio-demographic and other characteristics were collected by a questionnaire developed specifically for this study. It included questions about the parent's employment status, mother's age and level of education, ethnicity and household income. Other information such as the child's age, gender and disease duration (in years) was abstracted from the medical chart.

4.1.3.4 Analysis

In our cohort we enhanced the sample power by taking advantage of the repetitive aspect of the study and included all time intervals in our analysis.

Univariate analyses were conducted to describe baseline characteristics of the sample and to examine distributions of different variables. These characteristics were also used to compare participants and non-participants at baseline, 6-month and 12-month intervals. Mean and standard deviation of coping

patterns were also calculated at these three time periods. Multivariate analyses using Linear Mixed Models were conducted to determine associations between functional severity of the child and each of 1) parental coping pattern and 2) parental psychological distress, adjusting for relevant socio-demographic characteristics of interest and those mentioned in the literature review: child's age, sex and perception of pain severity; parent's employment status, mother's age and education, family structure and socio-economic status, ethnicity, duration of the disease, family dynamics. We used two models to illustrate each of the above two research questions: in the first model total JAQQ score was the main independent variable, while in the second model four subscales of JAQQ were the main independent variables. In our analysis, we used Linear Mixed Model, which is a generalization of the standard linear model that allows to combine same subjects' data over the study period in one analysis. Furthermore, we used residual maximum likelihood as the method of parameter estimation with compound symmetry as the covariance structure based on Schwarz's Bayesian Information Criterion (33). All variables were treated as fixed-effect parameters except for the intercept, which was treated as a random-effect parameter.

Our initial models included all variables mentioned above. In a second run, variables with a p-value>0.2 were dropped. Then model selection was continued until all variables in the model attained a p-value<0.05. However, the main independent variable (Total JAQQ score or its four subscales) as well as age and sex variables were always forced in the models irrespective of their significance

value. Final model selection was based on the above criteria. To enhance comparability across the three models of family coping variables, we re-introduced all significant variables in either of three models into all our final models. The latter models are presented in the Tables 4 and 5. Analyses were performed using SPSS software version 14 (Chicago, Il) (34).

4.1.4 Results

Of the initial 235 parents who consented to participate, 182 (77.4%) returned questionnaires: 120 from Montreal and 62 from Vancouver. There were no significant differences between participants and non-participants at baseline on several socio-demographic variables such as child's age, age of disease onset and sex, mother's age, mother's education, mother's employment status, family income, family dynamics, family structure and cultural background (data not shown). However, the mean active joint count (ajc) was higher in children of participants (1.8 versus 0.6; p=0.001) compared to those of non-participants. At six months, respondents differed from non-respondents with respect to the severity of the child's dysfunction. Namely, non-respondents were more severely afflicted than respondents (data not shown). Finally, at twelve months a significantly greater number of non-participant children were older (11.4 versus 9.5 years) and with a longer duration of disease (5.0 versus 3.8 years) than participants.

Of the 182 parents who participated in our study each had a child with JIA. Mothers had a mean age of 39.6 (6.0) years. Only 25 parents (15.7%) presented with clinical psychological distress at baseline (Table 1). Each parent who responded had one child included in the study. Therefore in our sample there were 182 children with JIA in our sample, 69.2% were females. At baseline, the means (SD) for child's age and disease duration were 10.2 (4.4) years (range 2.0-18.0 years) and 4.2 (3.6) years (range 0.1-15.6 years), respectively. The percentage of children with each JIA classification was 44.5% oligoarthritis, 20.3% polyarthritis, 9.3% systemic arthritis, 9.9% enthesitis related arthritis, 10.4% psoriatic arthritis, and 5.5% other. Mean scores for the CHIP at baseline, six and twelve month follow-ups are presented in Table 2. At baseline, Understanding the Medical Situation was slightly more useful than Maintaining Family Integration, while Maintaining Social Support was the least useful coping pattern. Maximum score for each of these coping patterns were respectively 24, 57 and 54. Mean scores for each coping pattern remained relatively stable over the study period. Mean total JAQQ scores and subscale scores are presented at baseline, 6 months and 12 months (Table 3). These results show that the severity of the child's dysfunction falls off slightly following the six-month follow-up and remains relatively stable after that time interval.

Table 4 presents the three parental coping patterns against the total functional disability score (JAQQ). Age and sex adjusted results indicate an inverse significant relationship between total JAQQ score and Maintaining Social

Support coping pattern. Namely, a higher total JAQQ score was significantly associated with a decrease in the use of this coping pattern (β coefficient, -1.86; 95% CI, -3.16, -0.56). On the other hand, mother's education and Family dynamics were also significantly associated with certain parental coping patterns. For instance, lower mother's education (i.e. completed high school or not) was associated with more use of Maintaining Family Integration (β coefficient, 3.94; 95% CI, 0.75, 7.12) and Understanding the Medical Situation (β coefficient, 3.39; 95% CI, 1.44, 5.34), and better family dynamics were significantly associated (β coefficient, 4.44; 95% CI, 0.50, 8.37) with more use of the coping pattern of Maintaining Social Support.

With respect to the second model (Table 5), and among the four functional disability subscales, psychosocial and systemic symptoms were significantly related to only Understanding Medical Situation parental coping pattern. Mainly, families whose children had greater psychosocial dysfunction tended to use more behaviours classified as Understanding the Medical Situation coping pattern (β coefficient, 0.73; 95% CI, 0.01, 1.45). Also, greater frequency of systemic symptoms, were associated with less use of the same coping pattern (β coefficient, -0.81; 95% CI, -1.55, -0.06). Variables such as mother's education and family dynamics manifested associations similar to that of models in Table 4, and ethnicity attained significant level revealing that English Canadian families tended to find the coping pattern of Maintaining Social Support more useful (β coefficient, 6.79; 95% CI, 1.67, 11.92).

Table 6 summarizes relationships of functional disability appraisals with parental psychological distress. These models are also adjusted to child's age and gender. Results reveal that a higher score for child psychosocial difficulties was significantly associated (β coefficient, 0.39; 95% CI, 0.05, 0.73) with greater parental psychological distress and better family dynamics was associated with less parental psychological distress in both models (β coefficient, -2.58; 95% CI, -4.67, -0.48; β coefficient, -2.15; 95% CI, -4.20, -0.10).

4.1.5 Discussion

Parents of children who had more psychosocial dysfunction found that Understanding the Medical Situation was the most useful coping pattern. Furthermore, greater psychosocial dysfunction in children with JIA appears to be associated with a higher degree of parental psychological distress. On the other hand greater overall child dysfunction, as shown by higher total JAQQ scores and more frequent systemic symptoms, were significantly related to a decrease in use of certain parental coping patterns.

Parents whose children had more psychosocial difficulties used more coping behaviours related to Understanding the Medical Situation. Poor psychosocial function in children with juvenile rheumatic disease may impact parental depression and may increase emotional strain (35). Parents may seek information to enhance their understanding of their child's medical situation in an

attempt to improve their child's health and possibly help with their social integration. In comparison, parents whose children had more frequent systemic symptoms did not find it useful to use coping behaviours related to the pattern of Understanding the Medical Situation. These parents may be so overwhelmed by their child's disease, or possibly so well informed about the limitations of the medical interventions, that they do not find Understanding the Medical Situation useful.

A higher total JAQQ score was significantly associated with decreased use of coping behaviours related to Maintaining Social Support, indicating that the greater the functional disability, the less useful, parents find such behaviours as social services and participating in non-professional support groups. Parents may feel overwhelmed requiring more external social support than is available in order to cope with their family situation (9).

Our findings did not show a significant association between child's age and parental coping, partly corroborating those of Tak et al. who found no significant association between child's age and maternal coping among parents of children diagnosed with congenital heart disease (15). However, McCubbin reported that mothers rely less on seeking social support in older children than in younger children with cystic fibrosis (36). Our study has shown that mothers with lower levels of education seem to find the coping patterns of Maintaining Family Integration and Understanding the Medical Situation useful, which entails

completing activities with family members and asking doctors and other health professionals about their child's disease. Possibly mothers who have completed at most a high school degree are more dependent on external support given to them by family members and on information provided by the medical staff.

We found that the better the family gets along, the more useful parents find the coping pattern of Maintaining Social Support, possibly because family members know to work together to relieve strain by participating in social activities and by relying on each other as well as community resources for respite care. English Canadian families tended to find the coping pattern of Maintaining Social Support more useful. We can speculate that these families' cultural values allow them to appreciate participation in social activities and seek out community resources.

Although child's overall functional severity (total JAQQ score) was not related to parental distress, we did find that higher child psychosocial dysfunction was associated with higher parental distress. Lustig et al. reported that greater functional disease severity among children with juvenile rheumatoid arthritis (JRA) is associated with more psychological distress among mothers (14). Psychosocial dysfunction affects a child's interactions with parents, siblings, teachers and peers. These children may present with decreased participation in school and extra-curricular activities. Parents may feel more psychological distress in response to their child's limited social integration. Our results show

that the stronger the family dynamics the lower the level of parental psychological distress. We expect that the better the family gets along the better they can work together to cope with their family situation, consequently limiting parental psychological distress.

4.1.6 Study limitations

There are a number of limitations to these findings. Information on parental coping was based purely on parents' self-report of the usefulness of specified coping patterns. We were not able to examine whether the parents truly used the coping patterns or whether they are effective. Our results show that parents consistently found the same coping patterns useful throughout the study, leading us to believe that their reports were reliable. The severity of the child's dysfunction falls off slightly following the six-month follow-up. If those who dropped out of the study were also less inclined to use certain coping patterns, then this may have affected our results. However, our data supports the stability of the use of coping patterns over the three time periods. Although family dynamics is relevant to our analysis we only measured one component from the CHQ (i.e. how the family gets along) possibly limiting the validity. A single item was used to assess family dynamics, which may threaten the validity of this indicator. Although, we adjusted for age, sex, and related socio-demographic characteristics, there may be other factors that we did not measure that could potentially influence a child's functional severity and parental coping (e.g. parental dynamics, stress, the presence of other siblings either ill or healthy, the child's level of distress).

4.1.7 Conclusion

In conclusion, our results demonstrated that parents of children with JIA who have greater psychosocial dysfunction appear to find Understanding the Medical Situation more useful and experience more psychological distress. In addition, Understanding the Medical Situation is a coping pattern that was deemed most useful by the parents in this study. These findings may support the clinical implication of healthcare professionals as important sources of medical information for parents. On the other hand, more frequent systemic symptoms appear to deter parents from relying on Understanding the Medical Situation possibly due to the lack of successful communication between health care professionals and parents of children with JIA. These findings may support the need for clinicians to adopt effective techniques to help parents better understand their children's medical situation.

Table I: Baseline characteristics of parents and children from the JIA study sample (n=182).

	Mean (SD)
Parent's age (yrs)	
Mothers	39.6 (6.0)
Fathers	42.2 (6.6)
Child's age (yrs)	10.2 (4.4) range 2.0-18.0
Duration of Disease (yrs)	4.2 (3.6) range 0.1-15.6
Pain score (VAS)	16.9 (23.1)
Active joint count (ajc)**	1.8 (0.5)
	n *(%)
Child's sex	
Female	126 (69.2)
Maternal education	
No education beyond high school	60 (39.2)
Parent's employment status	
Working	106 (69.3)
Family structure	
One parent family	46 (26.6)
Two parent family	127 (73.4)
Parental psychological distress	
< 63	134 (84.3)
≥ 63 (high distress)	25 (15.7)
Household income (CAD)	
<35,000 $	25 (24.3)
35,000-64,999 $	40 (38.8)
≥65,000 $	38 (36.9)
Family Dynamics	
Excellent	21 (17.2)
Very good	65 (53.3)
Good	23 (18.9)
Fair	10 (8.2)
Poor	3 (2.5)
Ethnicity	
French Canadian	68 (39.1)
English Canadian	63 (36.2)
Other	43 (24.7)

*Excluding missing cases; Variable not included in linear mixed model analysis.

Table II: Mean (SD) Coping Health Inventory (CHIP) scores of parents at baseline, 6-month and 12-month study period.

	Baseline (n=162)		6-month (n=101)		12-month (n=98)	
	Total pattern score (SD)	% of maximum score	Total pattern score (SD)	% of maximum score	Total pattern score (SD)	% of maximum score
Maintaining Family Integration (max: 57)	38.4 (9.0)	67.4	37.4 (9.2)	65.6	36.3 (10.4)	63.7
Maintaining Social Support (max: 54)	33.4 (11.6)	61.9	33.8 (11.0)	62.6	33.4 (12.6)	61.9
Understanding the Medical Situation (max: 24)	16.5 (6.1)	68.8	16.3 (5.7)	67.9	15.1 (6.5)	62.9

Table III: Mean (SD) Juvenile Arthritis Quality of life Questionnaire (JAQQ) scores at baseline, 6-month and 12-month study period.

	Baseline (n=181)	6-month (n=120)	12-month (n=104)
Gross Motor	2.6 (1.8)	2.0 (1.5)	2.0 (1.5)
Fine Motor	1.6 (1.2)	1.2 (0.8)	1.2 (1.1)
Psychosocial	2.2 (1.3)	1.8 (1.4)	1.9 (1.2)
Systemic Symptoms	2.6 (1.3)	2.3 (1.5)	2.3 (1.4)
Total JAQQ score	2.2 (1.2)	1.7 (1.1)	1.8 (1.0)

Table IV: Association between severity (JAQQ total score) and coping (family integration, social support and medical situation) based on results of Linear Mixed Model Analysis.

	Model 1a ‡	Model 1b ‡	Model 1c ‡
	Maintaining Family Integration β (95 % CI)*	Maintaining Social Support β (95% CI)*	Understanding Medical Situation β (95% CI)*
Total JAQQ score	-0.78 (-1.80, 0.23)	-1.86 (-3.16, -0.56)**	0.08 (-0.65, 0.81)
Mother's education:			
- No education beyond high school	3.94 (0.75, 7.12)**	3.15 (-0.59, 6.88)	3.39 (1.44, 5.34)**
- Post-secondary education	reference	reference	reference
Family dynamics			
- Excellent to very good	0.39 (-2.73, 3.50)	4.44 (0.50, 8.37)**	0.44 (-1.76, 2.64)
- Good	-0.20 (-2.63, 2.23)	-0.95 (-4.04, 2.14)	0.06 (-1.68, 1.80)
- Fair to poor	reference	reference	reference
Ethnicity:			
- French Canadian	-0.20 (-4.23, 3.84)	3.91 (-0.83, 8.65)	-0.18 (-2.65, 2.29)
- English Canadian	1.35 (-2.95, 5.64)	6.21 (1.14, 11.29)	-0.91 (-3.59, 1.77)
- Other	reference	reference	reference

‡ These models are adjusted for age and sex variables but their β (95% CI) are not shown.

* β (95 % CI) = β coefficient and 95% confidence interval.

** p-value<0.05

Table V: Association between severity (four subscales of the JAQQ) and coping (family integration, social support and medical situation) based on results of Linear Mixed Model Analysis.

	Model 2a ‡	Model 2b ‡	Model 2c ‡
	Maintaining Family Integration β (95 % CI)*	Maintaining Social Support β (95% CI)*	Understanding Medical Situation β (95% CI)*
Gross motor	-0.24 (-1.10, 0.61)	-0.78 (-1.90, 0.33)	0.35 (-0.27, 0.97)
Fine motor	-0.17 (-1.20, 0.87)	-0.03 (-1.40, 1.33)	-0.38 (-1.16, 0.39)
Psychosocial	0.29 (-0.68, 1.26)	-0.18 (-1.45, 1.10)	0.73 (0.01, 1.45)**
Systemic symptoms	-0.69 (-1.72, 0.34)	-0.80 (-2.13, 0.52)	-0.81 (-1.55, -0.06)**
Mother's education:			
- No education beyond high school	4.13 (0.93, 7.32)**	3.45 (-0.32, 7.22)	3.32 (1.37, 5.27)**
- Post-secondary education	reference	reference	reference
Family dynamics:			
- Excellent to very good	0.55 (-2.57, 3.68)	4.54 (0.57, 8.51)**	0.68 (-1.52, 2.89)
- Good	-0.03 (-2.41, 2.48)	-0.63 (-3.76, 2.51)	0.14 (-1.61, 1.89)
- Fair to poor	reference	reference	reference
Ethnicity:			
- French Canadian	-0.27 (-4.34, 3.79)	3.96 (-0.83, 8.76)	-0.32 (-2.80, 2.17)
- English Canadian	1.66 (-2.66, 5.98)	6.79 (1.67, 11.92)**	-0.87 (-3.55, 1.81)
- Other	reference	reference	reference

‡ These models are adjusted for age and sex variables but their β (95% CI) are not shown.

* β (95% CI) = β coefficient and 95% confidence interval.

** p-value<0.05

Table VI: Association between total severity JAQQ score (model 1) or: four subscales of the JAQQ severity score (model 2) and parental distress based on results of Linear Mixed Model Analysis.

	Model 1‡	Model 2‡
	Parental distress (t-score GSI) β (95% CI)*	Parental distress (t-score GSI) β (95% CI)*
Total JAQQ score	0.14 (-0.24, 0.52)	N/A
Four subscales of the JAQQ	N/A	
Gross Motor		0.09 (-0.20, 0.39)
Fine Motor		-0.20 (-0.63, 0.23)
Psychosocial		0.39 (0.05, 0.73)**
Systemic symptoms		-0.07 (-0.38, 0.23)
Family dynamics:		
- Excellent to very good	-2.58 (-4.67, -0.48)**	-2.15 (-4.20, -0.10)**
- Good	-0.63 (-1.46, 0.21)	-0.28 (-1.02, 0.47)
- Fair to poor	Reference	Reference

‡ These models are adjusted for age and sex variables but their β (95% CI) are not shown.

* β (95% CI) = β coefficient and 95% confidence interval.

** p-value<0.05

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Article 4.2: Is Parental Coping Associated with Functional Severity in Children with Physical Disabilities?

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4.2.1 Abstract

OBJECTIVES: 1) To describe parental coping in a cohort of children with physical disabilities (PD); 2) to determine whether disease severity is associated with parental coping and; 3) to explore whether socio-demographic factors such as child's age, maternal education and family structure are associated with parental coping.

METHODS: Parents (mother or father) of 150 children with PD were interviewed after being referred to community rehabilitation services. They answered the following: the Coping Health Inventory for Parents (CHIP), the Functional Independence Measure for children (WeeFIM), the Family Empowerment Scale (service system subscale) and a study questionnaire that addressed socio-demographic characteristics. Multiple linear regression models were used to determine the association between disease severity and other factors and parental coping, as well as the effects of severity and other factors on parental empowerment.

RESULTS: Mean (SD) age of the children was 40.9 (15.2) months and 64.7% were male. Mean (SD) parental coping scores at baseline were 40.5 (7.6), 40.1 (6.5), 14.6 (3.9), for Maintaining Family Integration (maximum score 57), Maintaining Social Support (maximum score 54) and Understanding the Medical Situation (maximum score 24), respectively. Maintaining Social Support was deemed most useful. Parents of children with moderate to severe dysfunction in mobility (WeeFIM) used more coping behaviours related to Understanding the Medical Situation (β coefficient, 2.07; 95% CI, 0.37, 3.78). Greater perceived usefulness of Maintaining Social Support was associated with lower maternal education, working parents and two parent families. **CONCLUSION**: These findings underscore the importance of helping parents of children with PD maintain social support. It is important to help parents understand the medical situation, especially those whose children have more severe mobility dysfunction.

4.2.2 Introduction

Disability is defined as the substantial and long-term adverse effect a physical or mental impairment has on the person's ability to carry out day-to-day activities(1). Children with physical disabilities show greater social isolation and limited participation in age-appropriate activities including community and school-based activities (2). Furthermore, children with lower levels of function are more limited in participation (3;4). Child functional severity, or the ability to complete age-appropriate social and physical activities (5-7), may in turn, have an effect on maternal mental health (8) and can affect the parents' social activities and relationship with friends (9). Also, maternal depression appears to be positively correlated to the child's level of disability (10). Provision of regular care to children with physical disabilities is often physically and psychosocially demanding and can cause parental strain (11). To respond to the increasing demands of a stressful family situation, parents must rely on different coping behaviours to ensure adjustment and adaptation (12).

Many studies have examined how living with a child with a chronic condition exacerbates parental stress levels and hinders psychological adjustment (13-19), but little is known regarding the effect of severity of the child's disability on the choice of parental coping behaviours (16). Tak et al. showed no significant association between parental coping behaviours measured by the Coping Health Inventory for Parents (CHIP) and severity of the child's congenital heart disease (16). Tak et al. also found that parents may cope differently irrespective of disease

severity and that some families adapt better than others when faced with similar stressors (16). Further studies are necessary to determine psychological and social implications of the child's functional severity on the family to better parental coping.

Parental coping refers to an effort by which the parent attempts to reduce or manage the demands on the family system (12). Family stress theories purport that the family system is composed of the child, parent and family environment and that family adjustment and adaptation is a function of the family's ability to cope with demands and use various resources (family, social and healthcare related) (12;20).

The current study examined coping in parents living with a child with a physical disability (PD). We hypothesized that the child's functional severity will not influence parental coping patterns and that parents may rely on different coping behaviours to deal with the situation. We investigated characteristics that may influence parental coping through utilization of family, social and healthcare resources. These characteristics were related to the child (functional severity – the main independent variable, age, sex, and disease duration), the parent (mother's age, level of maternal education, parent's employment status) and the family environment (household income, family structure and family's cultural background).

The specific aims of this study were 1) to describe parental coping behaviours in a cohort of children with a PD, 2) to determine whether disease severity is associated with parental coping, and 3) to explore what socio-demographic factors are associated with parental coping. As an additional objective, we examined whether disease severity and socio-demographic factors are associated with parental empowerment.

4.2.3 Patients and methods

4.2.3.1 Participants

Parents, either the mother or the father, caring for a child with PD (n=150), 18-116.7 months of age, who were referred to occupational/physical therapy services from two Canadian pediatric hospitals (Montreal Children's Hospital (MCH)-McGill University Health Centre, n=80 and Hôpital Sainte-Justine's (HSJ)-Centre Hospitalier Université de Montréal, n=70) participated. Children with a disability due exclusively to a cognitive delay were excluded. Families resided in Montreal and surrounding areas (50-km radius). Parents were eligible for the study if they spoke and understood English or French.

4.2.3.2 Data Collection

This is a secondary analysis of data collected from parents participating in a larger study assessing waiting times for pediatric rehabilitation services in preschool-aged children. Parents of children with PD were approached while their child was followed as an out-patient by either OT or PT services at either tertiary

centre, they were then interviewed face to face and completed: 1) the Coping Health Inventory for Parents (CHIP), 2) the Functional Independence Measure for Children (WeeFIM), 3) the Pediatric Quality of Life Inventory PedsQL, 4) Family empowerment scale (FES) (service system subscale) and 5) a study questionnaire that included socio-demographic information. Data were collected at time of referral to rehabilitation services.

The study was approved by each of the two hospital's research ethics committees. Written parental informed consent was obtained for all participants.

4.2.3.3 Measures

The Coping Health Inventory for Parents (CHIP) was used to measure parental coping (21). This 45-item questionnaire is a valid and reliable measure by which parents indicate the type of coping behaviours they use in response to their child's illness, and how useful these behaviours are from not useful [0] to extremely useful [3]. This questionnaire is composed of three main coping patterns. The first coping pattern is *Maintaining family integration, cooperation, and an optimistic definition of the situation* (19 items, maximum score =57), which refers to, for example, parents participating in activities with other family members or getting other family members to help with chores and tasks at home. The second coping pattern is *Maintaining social support, self esteem, and psychological stability* (18 items, maximum score = 54), which refers to, for example, parents taking a break from the home care tasks and responsibilities for

some relief or talking to someone about how they feel. The third coping pattern is *Understanding the medical situation through communication with other parents and consultation with the medical staff* (8 items, maximum score = 24), which refers to, for example, parents talking with the medical staff (nurses, social worker, etc.) when visiting the medical centre or with the treating physician. Higher scores imply greater usefulness of that particular coping pattern. To allow for comparison between the three coping patterns, we determined the percentage of the maximum score per pattern. This percentage was calculated by dividing the total score for each coping pattern by the maximal possible score of that specific pattern. The internal consistency of the CHIP is good with Cronbach alphas of 0.79; 0.79; 0.71 for each pattern, respectively (21). The CHIP has fair concurrent validity and correlates with the Family Environment Scales (22). The test-retest reliability of the German version is 0.75, 0.63 and 0.57; respectively, for the three coping patterns and construct validity has been supported by correlations between the total score and the Trier scale, a multidimensional coping questionnaire for adult patients (23).

The Functional Independence Measure for Children (WeeFIM) evaluates disability and measures functional status in children with disabilities aged six months to 12 years of age (24). The WeeFIM is versatile in that in can be used by different professionals and is designed to assess disability (i.e. degree of performance of tasks) in performing self-care, mobility and cognition related tasks (25) in children with various diagnoses (24). Each subscale consists of two to six

items that are scored separately. An ordinal rating system ranging from complete independence [7] to total assistance [1] is used (26). The minimum possible rating is 18 (total dependence in all skills) and the maximum is 126 (complete independence in all skills) (26). Scoring consists of calculating quotients for the three subscales (self-care, mobility, cognition) and for the total score, with lower quotients representing higher levels of disability. A quotient of 75 or higher represents a mild disability, a quotient of 50 to 75 represents a moderate disability and that below 50 indicates a severe disability (27). Test-retest reliability is high for the three domains and total score, ranging from 0.89 to 0.99 (25). The interrater reliability is also good ranging from 0.87 to 0.95 for all domains and total WeeFIM score (25). Criterion-validity is supported by adequate Pearson correlations between the different WeeFIM scores and both the extra help and time needed by children to complete a certain activity compared to the norm (25).

The FES is a self-report questionnaire measuring the level of empowerment and the way that empowerment is expressed (28). The test consists of 34 items incorporating three subscales of empowerment: 1) family, which relates to the parents' efforts to manage their everyday demands, 2) service system, which refers to the parent and the service system working together to obtain the services the child needs, and 3) community/political, where the parent is an advocate for advancements and changes in the service delivery for children, in general. In our study, parents completed only the service system subscale (12 items). It explores parent's relationship with healthcare professionals involved in

their child's care and the level of comfort in asking questions and voicing their opinions. The items are scored using a five-point Likert scale from not true at all [1] to completely true [5] and a summary score can be generated for this subscale. The internal consistency (Cronbach alpha) of the service system subscale was 0.87 and the test-retest reliability was 0.77 (28). The validity of the three dimensions of empowerment has been confirmed (28).

The study questionnaire addressed socio-demographic characteristics and healthcare utilization, such as: district of residence, mother's educational level, family income, and receipt of rehabilitation services (PT and/or OT), including public and private sources.

4.2.3.4 Analysis

Univariate analyses were completed to describe baseline characteristics of the sample and to examine distributions of different variables. Multiple regression analysis determined the associations between functional severity of the child's condition (WeeFIM), and parental coping adjusted for variables based on the literature and those of interest as: child's age, gender, diagnostic group (global developmental delay versus specific diagnosis), OT and/or PT services received, maternal level of education (no education beyond high school versus post-secondary education), parent's employment status (working versus not working), family structure (one or two-parent), household income ($\leq$\$39,999, \$40,000-59,999 or $\geq$\$60,000), and ethnicity (French Canadian, English Canadian or other).

For both models the dependent variables were the three subscales of the CHIP. In the first model, the total WeeFIM score was the main independent variable, while in the second model, the scores for the three WeeFIM subscales were the main independent variables. Multiple linear regression models were also used to determine whether total functional severity score as well as its three domains were associated with parental empowerment (service system subscale).

Our initial models included all variables mentioned above. In a second run, variables with a p-value>0.2 were dropped. Model selection was then continued until all variables in the model attained a p-value<0.05. However, the main independent variable (Total WeeFIM score or its three subscales) as well as age, sex and diagnosis variables were always forced in the models regardless of their significance value. Final model selection was based on the above criteria. However, to enhance comparability across the three models of family coping variables, we re-introduced all significant variables in each of three models into all final models. The latter models are presented in Tables 3 and 4. Analyses were performed using SPSS software version 14 (Chicago, Il) (29).

4.2.4 Results

Of the 306 subjects initially eligible for the larger study, only 224 parents agreed to participate. For this analysis, we excluded 74 children who were younger than 18 months of age. The WeeFIM has low sensitivity for children younger than 18 months as supported by our preliminary analysis (data not shown)

and data from Msall et al. reporting that the WeeFIM is most useful for children of at least two years of age (24). Thus, our final sample was composed of 150 children with a PD. There were no differences between respondents and non respondents with respect to child's age ($t = 0.21$, $p= 0.83$), child's gender ($\chi^2 = 0.17$, $df =1$; $p=0.68$) and child's diagnosis (χ^2 2.96, $df =1$; $p= 0.09$).

There were 150 parents (mother or father) participating in the study each caring for a child with PD. Of these children, 65.6% were males and their mean (SD) age was 40.9 (15.2) months (range 18.1-116.7 months). As per the medical chart, the children had the following diagnoses (Table 1): 78 (52.0%) global developmental delay (GDD), 18 (12.0%) prematurity, 15 (10.0%) genetic syndromes other than Trisomy 21, 11 (7.3%) other neurological conditions, 11 (7.3%) cerebral palsy (CP), 7 (4.7%) seizures, 4 (2.7%) Trisomy 21 and 2(1.3%) spina bifida. Of the children in our study nearly fifty percent presented with mild dysfunction as described by their total WeeFIM score, whereas less than ten percent presented with severe dysfunction (Table 2).

Mean (SD) CHIP scores were 40.5 (7.6) for Maintaining Family Integration, 40.1(6.5) for Maintaining Social Support and 14.6 (3.9) for Understanding the Medical Situation, where the maximum score for each of these coping patterns is 57, 54 and 24, respectively. Maintaining Social Support was slightly more useful than Maintaining Family Integration and Understanding the

Medical Situation was the least useful coping pattern, as indicated by the percentage of maximum scores, 74.3, 71.1 and 60.8, respectively.

Tables 3 and 4 present the associations between parental coping patterns and functional severity, as well as other variables related to the child, the parent and the family environment. In model one, the main independent variable is the total WeeFIM score and in model two, there are three main independent variables representing each of the WeeFIM subscales.

Results from the first model (Table 3), show no significant associations between severity of the child's condition and parental coping as described by the CHIP's three coping patterns. However, lower maternal level of education (i.e. high school education or less) was significantly associated with greater use of all three coping patterns: Maintaining Family Integration (β coefficient, 3.19; 95% CI, 0.10, 6.28), Maintaining Social Support (CHIP) (β coefficient 4.24; 95% CI, 1.80, 6.68) and Understanding the Medical Situation (β coefficient, 1.78; 95% CI, 0.17, 3.39). Working parents tended to find Maintaining Family Integration (β coefficient 3.34; 95% CI, 0.35, 6.34) and Maintaining Social Support more useful (β coefficient 3.88; 95% CI, 1.51, 6.24). On the other hand, single parents did not find Maintaining Family Integration (β coefficient, -4.32; 95% CI, -8.21, -2.19) and Maintaining Social Support useful (β coefficient, -5.20; 95% CI, -8.13, -0.51).

The second model displays slightly different results (Table 4), where the severity of the child's dysfunction in mobility was significantly associated with the coping pattern Understanding the Medical Situation (β coefficient, 2.07; 95% CI, 0.37, 3.78). Once again, the coping pattern related to Maintaining Social Support was significantly associated with lower levels of maternal education (i.e. no education beyond high school) (β coefficient, 3.91; 95% CI, 1.61, 6.51) and if the parent worked (β coefficient, 3.68; 95% CI, 1.27, 6.08). Single parents did not find Maintaining Social Support useful (β coefficient, -5.03; 95% CI, -8.08, -1.97). Contrary to the first model, a lower level of maternal education was only related to Maintaining Social Integration (β coefficient, 3.91; 95% CI, 1.61, 6.51) and to Understanding the Medical Situation (β coefficient, 1.57; 95% CI, 0.01, 3.14)

At baseline, mean parental empowerment related to the system service subscale was 50.1 (6.5) (range from 27 to 60). None of the variables tested, including functional severity and socio-demographic characteristics, were associated with family empowerment (service system subscale).

4.2.5 Discussion

The majority of parents from our study found the coping pattern related to Maintaining Social Support most useful. Interestingly, only parents of children with greater dysfunction in mobility found Understanding the Medical Situation useful. This latter result differs from that of Tak et al. who found that parents

caring for a child with congenital heart disease tended to choose different parental coping patterns regardless of the severity of their child's condition (16).

Parents of children with functional limitations in mobility may seek out information to enhance their knowledge and understanding of their child's medical situation in an attempt to improve their child's physical function and their social integration. Children with physical disabilities show greater social isolation and limited participation in age-appropriate activities in the community and at school (2-4) which has an emotional and physical toll on parents (10;30).

Our study indicates that mothers with only a high school education (high school education or less) found Maintaining Social Support more useful. These mothers may not have many financial resources and may be dependent on social services to help with the care of their child. In addition, working parents found Maintaining Social Support useful, possibly relying on community services to help in the care of their child. Sallfors et al. found that social support helps parents caring for children with different disabilities to cope with their stressful situation (31). Mothers of children with spina bifida or cerebral palsy, who have a large social network of friends and family members providing psychological and material resources, have shown better psychological adjustment (32). On the other hand, single parents did not find Maintaining Social Support useful. These parents may have a limited social network and may not be able to find the time to seek out needed support due to the time consuming efforts of caring for their child alone.

In addition, mothers with a lower level of education tended to find Understanding the Medical Situation most useful. They may rely more on the medical staff and healthcare professionals for information regarding their child's diagnosis, prognosis and interventions, whereas others may use various sources (e.g. internet, social networking, alternative healthcare, private services, etc.). In general, obtaining necessary information from healthcare professionals may limit uncertainty and anxiety regarding their child's condition (31).

Functional severity of the child's disability was not associated with family empowerment (service system subscale). In Resendez' study, parents of children and adolescents with disabilities who had higher levels of function, felt more empowered and appreciated the services they received (33). Bennett et al. showed that parents of children with various developmental disabilities, who have positive relationships with service providers, also are more empowered (34). In our study, we did not measure parents' relationship with service providers, and the children in our study were actually on the waiting list for rehabilitation services, which may partly account for the discrepancies in results.

4.2.6 Study limitations

There are several limitations to our study. Information on parental coping was based on parents' self-report and we were not able to examine whether the parents truly used the coping patterns or whether they are effective. Although, we

adjusted for age, sex, diagnosis and socio-demographic characteristics, there may be other factors that we did not measure that could potentially influence a child's functional severity and parental coping. These could include parental and family dynamics, stress, the presence of other siblings (ill or healthy), and the child's level of distress.

4.2.7 Conclusion

In conclusion, our results demonstrated that Maintaining Social Support is the coping pattern deemed most useful by the parents in this study. However, single parents seemed unable to take advantage of social support and activities possibly due to their isolation and limited social network. As such, clinicians need to refer parents to community-based services to access, when needed, respite care or other services to ensure both the child's and the family's well being. In addition, parents of children with greater dysfunction in mobility found Understanding the Medical Situation most useful. This underscores the role of the healthcare professional in communicating with the parents, answering questions and providing information regarding available resources that parents may access. Our findings support the importance that parents attribute to obtaining information on social support and their child's medical situation. By identifying coping behaviours and the usefulness that parents attribute to them, we can guide parents of children with PD in finding appropriate services and information to improve care for their children.

Table I: Baseline characteristics of parents and children from the physical disabilities (PD) study sample (n=150).

	Mean (SD)
Child's age (months)	40.9 (15.2) range 18.1-116.7
Parental empowerment (system service subscale) (max score 60)	50.1 (6.5) range 27 - 60
	n *(%)
Child's sex: Males	97 (64.7)
Maternal education	
No education beyond high school	66 (44.9)
Parent's employment status	
Working	70 (63.6)
Family structure	
One parent family	29 (19.3)
Two parent family	121 (80.7)
Household income (CAD)	
≤$39,999	70 (48.3)
$40,000-59,999	37 (25.5)
≥$60,000	38 (26.2)
Ethnicity	
French Canadian	59 (40.4)
English Canadian	34 (23.3)
Other	53 (36.3)
OT services received	96 (82.1)
PT services received	58 (50.4)
OT or PT services received	107 (92.2)

* excludes missing cases

Table II. Severity of the child's dysfunction at baseline measured by the WeeFIM quotient scores (total WeeFIM and three subscales).

	Total WeeFIM	Self-Care	Mobility	Cognition
	n (%)	n (%)	n (%)	n (%)
Mild	73 (48.7)	56 (37.3)	93 (62.0)	43 (28.7)
Moderate	64 (42.7)	56 (37.3)	38 (25.3)	91 (60.7)
Severe	13 (8.7)	38 (25.3)	19 (12.7)	16 (10.7)

Table III: Association between total WeeFIM severity score and three subscales of the CHIP controlling for socio-demographic and family characteristics based on multiple linear regression backward selection results ‡.

	Model 1a‡	Model 1b‡	Model 1c‡
	Family Integration	Social Support	Medical Situation
	β(95% CI)*	β(95% CI)*	β(95% CI)*
Total WeeFIM score			
- Moderate-Severe	0.33 (-2.61, 3.26)	1.58(-0.74, 3.90)	0.05(-1.49, 1.58)
- Mild	Reference	Reference	Reference
Mother's education:			
- No education beyond high school	3.19(0.10, 6.28)**	4.24(1.80, 6.68)**	1.78(0.17, 3.39)**
- Post-secondary education	Reference	Reference	Reference
Parent's employment status:			
- Working	3.34(0.35, 6.34)**	3.88(1.51, 6.24)**	1.30(-0.26, 2.87)
- Not Working	Reference	Reference	Reference
Family structure:			
- One parent family	-4.32(-8.13, -0.51)**	-5.20(-8.21, -2.19)**	-1.68(-3.67, 0.31)
- Two parent family	Reference	Reference	Reference

‡ Age, sex and diagnosis variables are forced in these models but are not shown here.

* β (95% CI) = β Coefficient (95% confidence interval)

** p-value < 0.05

Table IV: Association between scores of the three WeeFIM subscales and three subscales of the CHIP controlling for socio-demographic and family characteristics based on multiple linear regression backward selection results‡.

	Model 2a‡	Model 2b‡	Model 2c‡
	Family Integration	Social Support	Medical Situation
	β(95% CI)*	β(95% CI)*	β(95% CI)*
Self-Care			
- Moderate-Severe-	-2.62(-5.97, 0.73)	0.74(-1.99, 3.47)	-1.38(-3.13, 0.37)
- Mild	Reference	Reference	Reference
Mobility			
- Moderate-Severe	2.21(-1.07, 5.49)	0.27(-1.40, 3.95)	2.07(0.37, 3.78)**
- Mild	Reference	Reference	Reference
Cognition			
- Moderate-Severe	-2.78(-5.99, 0.43)	-1.51(-4.13, 1.11)	-0.99(-2.67, 0.68)
- Mild	Reference	Reference	Reference
Mother's education:			
- No education beyond high school	2.82(-0.37, 5.66)	3.91(1.61, 6.51)**	1.57(0.01, 3.14)**
- Post-secondary education	Reference	Reference	Reference
Parent's employment status:			
- Working	-3.57(-0.12, 5.76)	3.68(1.28, 6.08)**	1.09(-0.45, 2.62)
- Not Working	Reference	Reference	Reference
Family structure:			
- One parent family	-2.28(-7.33, 0.18)	-5.03(-8.08, -1.97)**	-1.40(-3.36, 0.56)
- Two parent family	Reference	Reference	Reference

‡ Age, sex and diagnosis variables are forced in these models but are not shown here.

* β (95% CI) = β Coefficient (95% confidence interval)

** p-value < 0.05

Table V: Association between total WeeFIM severity score (model 1) as well as scores for the three subscales of the WeeFIM (model 2) and parental empowerment (service system subscale) based on multiple linear regression backward selection results ‡.

	Model 1‡	Model 2‡
	Parental empowerment β (95% CI) *	Parental empowerment β (95% CI) *
Total WeeFIM score		N/A
- Moderate-Severe	-0.02 (-2.23, 2.18)	
- Mild	reference	
Self-Care	N/A	
- Moderate-Severe		-0.27(-2.84, 2.31)
- Mild		Reference
Mobility	N/A	
- Moderate-Severe		-0.68(-3.22, 1.85)
- Mild		Reference
Cognition	N/A	
- Moderate-Severe		-0.73 (-3.20, 1.73)
- Mild		reference

‡ Age, sex and diagnosis variables are forced in these models but are not shown here.

* β (95% CI) = β Coefficient (95% confidence interval)

** p-value<0.05

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CHAPTER 5-DISCUSSION

In this section, the main results are summarized. This is through comparison between the two cohorts and with the literature followed by a discussion of the results. Finally, we discuss the role of rehabilitation professionals in parental coping and the need for specific strategies enabling parental coping.

In this study, parents from both cohorts reported using family, social and healthcare related coping behaviours as indicated by their mean maximum percentage CHIP scores, but to varying degrees. Parents of children with JIA found Understanding the Medical Situation most useful, whereas parents of children with PD found Maintaining Social Support most useful. In addition, different functional limitations (i.e. disease severity) for each cohort were positively associated with parental coping. Parents of children with JIA with the greatest psychosocial dysfunction and those with children with greater dysfunction in mobility from the PD cohort both found Understanding the Medical Situation most useful. The more the parent perceived their child's psychosocial or mobility dysfunction as severe, the more they sought out medical information from healthcare professionals, possibly in an attempt to better their child's situation. Certain authors purport that the psychosocial and physical ramifications on parent and child, rather than different medical diagnoses, may influence parental coping (16;17), which seems to support our findings. Finally, a lower level of maternal education (no education beyond high school) was the only socio-demographic

factor associated with parental coping in both cohorts. Factors that may explain these differences as well as comparisons with the literature are presented.

There may be several factors that influence preferences for parental coping, such as: nature of the child's condition, time of diagnosis, and healthcare services received by children. Some of these aspects may account for the differences in preferences observed between the two cohorts in our study.

The majority of children in the PD group had a global developmental delay; the multidimensional nature of this diagnosis makes diagnostic confirmation difficult (102). Consequently, parents may become stressed and frustrated with the lack of conclusive information provided by healthcare professionals on their child's condition (103). In comparison, parents of children with more definitively diagnosed medical conditions such as JIA rely on healthcare professionals to help monitor medication and specific exercises to help alleviate pain, stiffness and other associated symptoms. These parents found it most useful to communicate with the medical staff and healthcare professionals concerning their child's condition and the interventions that may better it. Parents caring for children with juvenile arthritis have stressed the importance of receiving support from healthcare professionals and utilizing them as an important source of information regarding the understanding and management of their child's chronic condition (72;77).

Although parents in the JIA cohort were following active treatment and were known to the clinic for some time, children with PD had for the most part been recently diagnosed and were not yet receiving publicly funded rehabilitation services. They were referred to community services and were put on waiting lists often exceeding seven months (76). Nevertheless, some received private occupational therapy and physiotherapy; these private services were not covered by the universal provincial health insurance, and necessitated out of pocket expense by the parents, which in some cases, could have caused some stress due to possible financial burden. Qualitative studies have shown that near the time of diagnosis parents find speaking to healthcare professionals about their child's new diagnosis helpful, as well as referral to social support (respite care, support groups) and formal emotional support (psychologist) (104-106). However, parents in the PD cohort found seeking social support more useful than speaking to healthcare professionals and medical specialists. Once again, this result could be related to the fact that these children generally were not receiving active rehabilitation services. Perhaps, in our cohort, it is the availability of services offered to children that impact parental coping patterns.

Barlow et al. found that inadequate support and lack of information prevented the parents from coping with their child's rheumatic illness (juvenile chronic arthritis) (77). Parents of children with JIA were followed regularly at their hospital rheumatology clinic (composed of nurse, rheumatologist, occupational therapist and physiotherapist). Parents could refer their questions to

their affiliated nurse and rheumatologist and were seen, on average, every three months. When information from healthcare professionals is readily accessible to parents such as with the JIA cohort, they tend to appreciate and find most useful to communicate with healthcare professionals as a means of informal emotional support and health related information (72).

On the other hand, children with PD were not followed regularly by hospital healthcare professionals; their parents did not find it helpful to speak with healthcare professionals about their child's condition possibly due to the lack of such contact. Instead these parents found relying on social support most useful. In order to adapt to their child's ongoing developmental delays these parents may require the assistance of community resources to help with daycare, school and respite care to manage the demands on the family (4) and these may be of greater assistance than the healthcare professionals.

Age differences between the cohorts may have contributed to the different associations between functional severity and parental coping. The children in the JIA cohort were older (mean age 10.2 ± 4.4 years) than those in the PD cohort (mean age 3.4 ± 1.3 years). For the JIA cohort, being older could relate to the fact that psychosocial limitations may hinder their age-appropriate roles. Most of the children in the PD cohort were pre-school age, and in all likelihood, were not yet participating in independent social activities; they were more at the stage of achieving important motor developmental milestones such as walking. These age-

related limitations may have impacted the choice of parental coping. Moderate to severe difficulties with mobility, such as any persistent difficulty in walking, may be indicative of morbidity in pre-school aged children. A study on high risk infants found that 56% of these children who were not walking by 18 months had associated abnormality diagnosed before 3 years (107). Delays in their child's development may have parents raising questions about their child's prognosis and possible medical interventions. Parents whose young children have more severe motor disabilities may find that talking to their treating physicians and the other healthcare professionals involved may be useful. This may explain the association with motor disability and use of the coping pattern related to Understanding the Medical Situation.

Interestingly, only one parent-related socio-demographic factor (i.e. maternal education) was significantly associated to greater perceived usefulness of specific parental coping patterns in both cohorts. Less than half of mothers from either cohort had an educational level of at most a high school degree. Mothers with a lower level of education in the JIA cohort found Maintaining Family Integration and Understanding the Medical Situation most useful, whereas mothers with a lower level of education caring for children with a PD found Maintaining Social Support and Understanding the Medical Situation most useful. Mothers of children with JIA ask their doctors about the advantages and side effects of new medication intended to relieve their child's recurring symptoms like inflammation, pain and nausea (77). Also, these same mothers often rely on family members to

help manage the demands of the disease on the family. Mothers of children with a PD appear to rely on information and services provided by the healthcare system, as well as by the community, such as respite care and other social services to ease the burden of caring for their child possibly to help limit their stress level (73).

In either case, mothers may be more dependent on family for support, healthcare professionals for information, as well as support from an external social network. The relationship between mother's level of education and parental coping is not easily explained. Mother's level of education by association can be indicative of her level of socio-economic status (108). As such we believe that a lower socio-economic status may make mothers less self-reliant, and consequently more dependent on the different available resources. In addition these mothers may be at higher risk of psychological maladjustment and poor social integration making it crucial that healthcare professionals refer to the adequate social services (e.g. respite care).

5.1 Study limitations

There are a number of limitations to this study. First, the use of different measures of functional severity in the two cohorts may account for some of the differences of the impact of severity on parental coping and limit the comparisons that can be made between the two cohorts with regards to severity. Although we used two validated tools, the JAQQ is specific to JIA, whereas the WeeFIM is a

more generalized measure of child function and burden of care. Second, although the regression models were adjusted for child's age, perhaps it would have been better to restrict our sample to pre-school aged children for better comparisons and avoidance of age-severity interactions. Third, information on parental coping was based purely on parents' self-report of the usefulness of specified coping patterns. We were not able to examine whether the parents truly used the coping patterns or whether they were effective. Finally, despite the fact that we adjusted for age, sex, and socio-demographic related characteristics in both cohorts, there may be other factors that we did not measure that could potentially influence a child's functional severity and parental coping. These could include parental and family dynamics, stress, the presence of other siblings (ill or healthy), and the child's level of distress.

5.2 Clinical implications

The findings of this study may have clinical implications for parents caring for a child with a chronic condition. Understanding the Medical Situation and Maintaining Social Support were found most useful by parents with children with JIA and those with a PD, respectively. As healthcare professionals, occupational and physical therapists have an important role in helping parents cope with the demands of their child's condition by providing valuable information about their child's condition and developmental progress, interventions (home programs, rehabilitation services) and available community social services (support groups, respite care).

Clearly children with JIA and those with PD require rehabilitation services (29;30;109-111). In the past decade, pediatric rehabilitation professionals (occupational therapists and physiotherapists) have reshaped their approach to intervention by making it more family-centred (109;112). More and more parents are now recognised as key players in their child's treatment. Although parents do play a major role in advocating for their child, clinicians must be aware of the potential stress that these new responsibilities can have on unprepared parents (112). Clinicians can help ease parents into their new complex role.

Effective knowledge transfer from clinician to parent is an important element of a family-centered approach. In a qualitative study by Barlow et al. on parents of children with juvenile arthritis, findings highlighted how valuable the transfer of information from healthcare professional to parent is for the parent's well-being (77). A chronic condition has the potential to hinder a child's social and physical functioning and parents need to acquire knowledge concerning their child's progression in therapy, additional community-based and social services, as well as potential respite care providers. Unfortunately, in past surveys, parents have reported that the transfer of general information from professional to parent is poor (113;114). Effective communication techniques are sorely needed, such as active listening i.e. taking the time to explore parents' concerns and questions regarding their child's care (72). According to Sallfors et al., the most appreciated

professionals by parents of children with chronic conditions are those who take the time to explain things in terms that parents can understand (72).

Another pressing issue in family-centred care is limited consensus between treating professionals on possible diagnoses and needed services for the child and family. Jones et al.'s findings showed that parents of children with developmental disabilities reported discrepancies in information given by the professionals involved in their child's care (103). It is essential that clinicians work together (i.e. to use an interdisciplinary rather than only a multidisciplinary approach) to help limit parental stress and provide quality care to families.

Occupational therapists and physiotherapists' role in parental coping is not limited to information provision, but also includes referring parents to the appropriate emotional/psychological supports (e.g. support groups, psychologist), as well as respite care offered by health and social service centres and other community or volunteer agencies. Ellis et al. maintain that parents of children with a developmental disability can participate in support groups composed of parents living a similar situation to share their experiences (1), which may in turn benefit the child's health by helping parents enhance self-esteem, manage psychological tension and obtain the needed social support (79). Providing guidelines and information may not be enough for certain parents and referral to community workers, such as social workers, may be crucial in helping parents get the help they need.

Our findings have given us some insight on what coping patterns parents of children with chronic conditions utilize and possible avenues for healthcare professionals to aid with the parents' adaptation to their family situation. Further studies are needed to identify the best service delivery approaches and possible communicating skills training for professionals to favour parental coping.

5.3 Conclusion

In conclusion, results from both cohorts showed that severity of the child's disability had an impact on parental coping. Parents of children with JIA found communicating with the medical professionals most useful, whereas parents of children with PD relied mostly on external social support to help cope with the demands of their family situation. The differences in the cohorts' characteristics (age, type of chronic condition, services received) may have influenced adoption of varying parental coping behaviours. Parents of children with greater dysfunction in either psychosocial or mobility skills found it useful to talk with the medical staff about their child's condition.

Our findings underscore the role of healthcare professionals in communicating with parents, answering questions and providing information regarding the available resources that parents may access. Healthcare professionals are important sources of crucial information for parents and our results support the need for clinicians to adopt effective communication techniques to help parents cope with their child's health situation.

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APPENDIX I: Ethics Committee Approval Certificates

Centre universitaire de santé McGill
McGill University Health Centre

THE MONTREAL CHILDREN'S HOSPITAL
RESEARCH ETHICS BOARD

The Research Ethics Boards (REBs) of the McGill University Health Centre are registered REBs working under the published guidelines of the Tri-Council Policy Statement, the "Plan d'action ministériel en éthique de la recherche et en intégrité scientifique" (MSSS, Qc), and in compliance with standards set forth in the (US) Code of Federal Regulations governing human subjects research, and act in conformity with the international standards of Good Clinical Practice: Consolidated Guideline (GCP E6).

A Montreal Children's Hospital Committee consisting of:

Jane McDonald, M.D., Chairperson	Microbiology
Gordon Watters, M.D., Co-chairperson	Neurology
Kathleen Glass, DCL, Co-chairperson	Ethics/Law
Janet Rennick, Ph.D.N.	Nursing
Laurel Kimoff, M.D.	Pediatrics
Carol Schopflocher, M.Sc.	Psychology
Sharon Vance	Community
Colombe Blais	Pharmacy

reviewed on December 18th, 2000 the research project entitled:

Determinants of Outcomes in Juvenile Idiopathic Arthritis

submitted by: Dr. C. Duffy

and consider it to be within acceptable limits of clinical investigation solely from the point of view of medical ethics. The following conditions apply to the ethical approval of the above-named study:

1. Receipt of scientific approval by the McGill University/Montreal Children's Hospital Research Institute.
2. Final approval of the IRB, i.e. the dated and signed IRB stamp on the French and English versions of the consent form will confirm scientific approval from the Research Institute.
3. If applicable, the contractual agreement must be signed by the appropriate authorities before the study can proceed.
4. The study is approved for a period of one year from the date shown below.
5. Prior to the end of the one-year period, the investigator(s) must advise the Institutional Review Board of the number and status of participants enroled in the study. We wish to be advised promptly of any significant adverse outcomes.
6. The investigator(s) must inform the Institutional Review Board should any changes be made to the study protocol and/or consent form.
7. Investigator(s) must notify the IRB of the starting date of the protocol and the date the study is completed. The IRB reserves the right to examine your study data, including signed

[redacted]

Jane McDonald, M.D., F.R.C.P©
Chairperson
Research Ethics Board

August 30, 2001
Date

cc: Ms. Alison Burch, MCH Research Institute

Centre universitaire de santé McGill
McGill University Health Centre

February 26, 2003

Dr. D. Feldman
Physiotherapy Department
Montreal Children's Hospital

Dear Dr. Feldman,

Re. Comparison of the Perception of Children with Juvenile Arthritis and of Their Parents regarding Compliance to Treatment and its Impact on Quality of Life (CIHR – Determinants of Outcomes in Juvenile Idiopathic Arthritis)

We are writing in response to your request for review, by the Chair of the Montreal Children's Hospital *REB*, of the component for the above-named study comparing reported adherence by parents and children as well as comparing parent reported and child reported quality of life, sing the JAQQ – Juvenile Arthritis Quality of Life Questionnaire.

We are pleased to inform you that the above-mentioned component, questionnaires, consent and assent form (English version) were found to be within ethical guidelines for conduct at the McGill University Health Centre. Approval for the documents was provided via expedited review of the Chair on February 25, 2003 and will be reported at the March 24, 2003 REB meeting and entered in the minutes.

The Research Ethics Boards (REBs) of the McGill University Health Centre are registered REBs working under the published guidelines of the Tri-Council Policy Statement, in compliance with the "Plan d'action ministériel en éthique de la recherche et en intégrité scientifique" (MSSS, 1998) and the Food and Drugs Act (7 June, 2001), acting in conformity with standards set forth in the (US) Code of Federal Regulations governing human subjects research, and functioning in a manner consistent with internationally accepted principles of good clinical practice. We wish to advise you that this document completely satisfies the requirement for Research Ethics Board Attestation as stipulated by Health Canada.

The English version of the consent and assent forms was approved on February 25, 2003 by Dr. J. McDonald, Chair of the REB. These forms must also be translated and validated before final ethical approval can be given. **The French version of the consent form must be submitted along with the English version of the form by e-mail (madeleine.hollingdrake@muhc.mcgill.ca), so that they can be forwarded to the MUHC translator for validation.**

We ask you to note that all research involving human subjects requires review at a regular interval and approval for the study will remain in effect until February 25, 2004 (anniversary of initial review). It is the responsibility of the principal investigator to submit an application for Continuing Review before the expiration date of the study approval.

Sincerely,

[redacted]

Madeleine Hollingdrake, Coordinator for
Jane McDonald, M.D., F.R.C.P©
Chair,
Montreal Children's Hospital Research Ethics Board

JM/mh

LE COMITÉ D'ÉTHIQUE DE LA RECHERCHE

Un comité de l'Hôpital Sainte-Justine formé des membres suivants:

Jean-Marie Therrien, président

Anne-Claude Bernard-Bonnin, pédiatre

Geneviève Cardinal, juriste

Daniel Caron, représentant du public

Hugues Charron, infirmier de recherche

Josette Champagne, hémato-oncologue

Françoise Grambin, représentante du public

Andréa Maria Laizner, scientifique

Suzanne Lépine, psychiatre

Lyne Pedneault, pharmacienne

Andrea Richter, scientifique

Chantal Van de Voorde, représentante du public

CENTRE
DE RECHERCHE
DE L'HÔPITAL
SAINTE-JUSTINE
Le centre hospitalier universitaire mère-enfant

Pour l'amour des enfants

Approbation valide pour une durée d'un an

Les membres du comité d'éthique de la recherche ont étudié le projet de recherche clinique intitulé:

Effects of Transfer Delay to Rehabilitation Services for Children / L'impact du délai de transfert vers les services de réadaptation pédiatrique pour les enfants.

soumis par: *Julie Gosselin Ph. D., co-investigateur et Debbie Feldman, Ph.D. (principal investigateur). Autres co-investigateurs: Bonnie Swaine, Ph.D., François Champagne, Ph.D. et Raynald Pineault, Ph.D.*

et l'ont trouvé conforme aux normes établies par le comité d'éthique de la recherche de l'Hôpital Sainte-Justine. Le projet est donc accepté par le Comité.

[redacted]

Jean-Marie Therrien, Ph.D., éthicien
Président du Comité d'éthique de la recherche

Date d'approbation: 06 juin 2002

3175, Côte-Sainte-Catherine
Montréal (Québec)

Centre universitaire de santé McGill
McGill University Health Centre

June 27, 2002

Dr. D. Feldman
Physiotherapy Department
Montreal Children's Hospital

Re. MCH002-16 Access to rehabilitation for children with physical disabilities

Dear Dr. Feldman,

The research proposal entitled above received Full Board review at the convened meeting of the Montreal Children's Hospital Research Ethics Board on May 27, 2002, was found to be within ethical guidelines for conduct at the McGill University Health Centre, and was entered accordingly into the minutes of the Research Ethics Board (REB) meeting. At the MUHC sponsored research activities that require US federal assurance are conducted under Federal Wide Assurance (FWA) 00000840.

We are pleased to inform you that final approval for the clinical protocol, the informed consent documents and informed assent documents was provided on June 25, 2002.

All research involving human subjects requires review at a recurring interval and the current study approval is in effect until May 27, 2003. It is the responsibility of the principal investigator to submit an application for Continuing Review to the REB prior to the expiration of approval, to comply with the regulation for continuing review of "at least once per year".

Any further modification to the REB approved and certified consent document must be identified by a revised date in the document footer, and re-submitted for review prior to its use.

The Research Ethics Boards (REBs) of the McGill University Health Centre are registered REBs working under the published guidelines of the Tri-Council Policy Statement, in compliance with the "Plan d'action ministériel en éthique de la recherche et en intégrité scientifique" (MSSS, Qc) and the Food and Drugs Act (7 June, 2001), acting in conformity with standards set forth in the (US) Code of Federal Regulations governing human subjects research, and functioning in a manner consistent with internationally accepted principles of good clinical practice.

We wish to advise you that this document completely satisfies the requirement for Research Ethics Board Attestation as stipulated by Health Canada.

The project was assigned Montreal Children's Hospital REB Study Number MCH002-16 that is required as MUHC reference when communicating about the research. Should any revision to the research, or other unanticipated development occur prior to the next required review, you are obligated to report in writing promptly to the REB. It is not permitted by regulation to initiate a proposed study modification prior to REB approval.

Sincerely,,

[redacted]

Jane McDonald, M.D., F.R.C.P©
Chair
Montreal Children's Hospital Research Ethics Board

Cc: Danuta Rylski, MCH RI

APPENDIX II: Consent Forms

Determinants of Outcomes in Juvenile Idiopathic Arthritis

Informed Consent (for parents of children with Juvenile Idiopathic Arthritis (JIA))

Investigators: Dr. Ciarán Duffy, The Montreal Children's Hospital; Dr. Debbie Feldman, L'Université de Montréal; Dr. Ann Clarke and Dr. Patricia Dobkin, The Montreal General Hospital

Funding Source: The Canadian Arthritis Network

Objectives of the Study

The goals of the study are: (1) to identify factors that may influence disease activity and quality of life in children with Juvenile Idiopathic Arthritis (JIA); and (2) to document the use of health services and school attendance.

Procedures

Your participation in this study involves three phases carried out over six months.

Phase 1: You will be asked to complete a series of questionnaires about your child's quality of life, adherence to prescribed treatments, the use of alternative therapies for your child's arthritis, as well as ways of coping with your child's illness. You will be asked about your general well-being, your family's economic situation, your use of medical services and school attendance in relation to your child's arthritis. A member of our research team will explain these questionnaires to you during your child's clinic visit. You will have the option of completing the questionnaire package in clinic or at home. If you choose to complete the package at home, you will be provided with a pre-addressed stamped envelope. Each questionnaire takes about 10 to 20 minutes to complete for a total of about 1 to 1½ hours.

You will also be asked to provide us with the names of three parents whose children are the same age (plus or minus one year) and sex as your child, but who do **NOT** have any rheumatic diseases. Please include one friend of your child's and one child of a work colleague. The third name can come from other sources (example: relative, neighbourhood friend). The parents of these children will be asked to contact us if they are interested in taking part. You will be asked to provide these parents with an invitation letter, which briefly describes their involvement in this study.

Phase 2: Your child will return to the Rheumatology Clinic three months after his/her initial enrolment into the study. He/she will be examined again by the rheumatologist as part of a regular follow-up visit. You will also be asked to complete the questionnaires a second time and then

return them using the pre-addressed stamped envelope provided. Each questionnaire takes about 10 to 20 minutes to complete for a total of about 1 to 1½ hours.

Phase 3: Six months after your child has been enrolled into the study, you will receive the questionnaire package again. You will be asked to complete the questionnaires and then return them using the pre-addressed stamped envelope provided. Each questionnaire takes about 10 to 20 minutes to complete for a total of about 1 to 1½ hours.

In addition, a research assistant may look through your child's medical chart to obtain basic clinical information (example: diagnosis and duration of disease).

Confidentiality

All information gathered during this study will be kept completely confidential. Your name/your child's name will not appear on the questionnaires. Your child's doctor and all other health professionals at the clinic will not be able to link your questionnaire answers to you or your child. You and your child will not be identified in any publication, which may result from this study.

The Internal Review Board (IRB) at The Montreal Children's Hospital may review the data gathered during this study. This is done to make sure that the guidelines put forth by the IRB are respected.

Benefits

Participating in this study will have no direct benefits to your family. However, the information provided by you will eventually help the doctors and therapists improve treatment and the quality of life in children with Juvenile Idiopathic Arthritis.

You will be given $10 to cover the cost of travel and/or parking at the 3-month clinic visit. In addition, for every envelope you return your name will be entered in a lottery. Five names will be drawn at random *every month* and the winners will receive prices valued at 10$.

Risks

Your participation in this study does not involve any foreseeable risks to you or your family.

Voluntary Participation

Your participation in this study is voluntary. You are free to refuse to answer any question, or to refuse to participate or withdraw from the study at any time. This will not affect the level of care received by your child at The Montreal Children's Hospital.

If you have any questions about your rights as a patient or any complaints about this study, please contact Elizabeth Gibbon [redacted]. If you have any questions about this study, please contact Dr. Ciaran Duffy [redacted].

Determinants of Outcomes in Juvenile Idiopathic Arthritis

Informed Consent (for parents of children with Juvenile Idiopathic Arthritis (JIA))

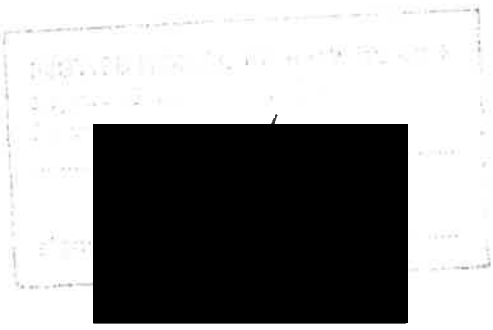
I acknowledge that the research procedures as described in this consent form have been explained to me and that any questions I have asked have been answered to my satisfaction. I understand that participation is voluntary. I am aware of my right to withdraw from the study at any time without compromising the level of care received by my child, at The Montreal Children's Hospital.

A copy of the consent form will be given to me.

The possible risks and discomforts, as well as the possible benefits of participating in this study have been explained to me.

All information will be kept strictly confidential and your child's anonymity will be preserved.

Participant's Name	Signature of Child (if older than 7 years)	Date (y/m/d)
Parent/Guardian's Name	Signature	Date (y/m/d)
Witness's Name	Signature	Date (y/m/d)
Investigator's Name	Signature	Date (y/m/d)



Déterminants des Résultats en Arthrite Juvénile Idiopathique

Consentement Libre et Éclairé (pour parents d'enfants atteints d'Arthrite Juvénile Idiopathique (AJI))

Chercheurs: Dr. Ciaran Duffy, L'hôpital de Montréal pour enfants; Dr. Debbie Feldman, L'Université de Montréal; Dr. Ann Clarke et Dr. Patricia Dobkin, L'hôpital général de Montréal

Source de financement: Le Réseau Canadien De l'Arthrite

Objectifs de l'étude

Les buts de l'étude sont: (1) d'identifier les facteurs pouvant influencer l'activité de la maladie et la qualité de vie des enfants atteints d'Arthrite Juvénile Idiopathique (AJI); et (2) de documenter l'usage des services de santé et la présence scolaire.

Procédures

Votre participation à cette étude comprend trois étapes au cours d'une période de six mois.

Étape 1: Nous vous demanderons de compléter une série de questionnaires portant sur la qualité de vie de votre enfant, l'observance des traitements prescrits, l'usage de thérapies alternatives concernant l'arthrite de votre enfant, ainsi que les façons de gérer le fait d'avoir un enfant qui souffre de cette maladie. Il y aura aussi des questions concernant votre bien-être en général, la situation économique de votre famille, la présence scolaire de votre enfant et votre usage de services médicaux en ce qui concerne l'arthrite de votre enfant. Un membre de notre équipe de recherche vous expliquera ces questionnaires lors de la visite de votre enfant à la clinique. Vous aurez le choix de compléter le paquet de questionnaires à la clinique ou à la maison. Si vous choisissez de le compléter à la maison, vous obtiendrez une enveloppe pré-adressée et pré-affranchie. Chaque questionnaire prend environ 10 à 20 minutes à compléter pour un total d'environ 1 heure à 1 heure et demie.

Nous vous demanderons aussi de nous fournir les noms de trois parents d'enfants ayant le même âge (plus ou moins un an) et le même sexe que votre enfant, mais qui ne souffrent **PAS** d'une maladie rhumatismale. Veuillez inclure un(e) ami(e) de votre enfant et un(e) enfant d'un(e) collègue de travail. Le troisième nom peut provenir d'autres sources (exemple: parenté, ami(e) du voisinage). Nous demanderons aux parents de ces enfants de nous contacter s'ils sont intéressés à participer. Nous vous demanderons de leur donner une lettre d'invitation décrivant brièvement leur participation à cette étude.

Étape 2: Trois mois après le début de la participation de votre enfant à l'étude, il/elle retournera à la clinique de rhumatologie. Il/Elle sera examiné(e) de nouveau par le rhumatologue, ceci faisant partie d'une visite régulière. Nous vous demanderons aussi de compléter les questionnaires une seconde fois et de nous les retourner en utilisant l'enveloppe pré-adressée et pré-affranchie fournie.

Chaque questionnaire prend environ 10 à 20 minutes à compléter pour un total d'environ 1 heure à 1 heure et demie.

Étape 3: Six mois après la participation initiale de votre enfant à l'étude, vous recevrez les questionnaires de nouveau. Nous vous demanderons de compléter ces questionnaires et de nous les retourner en utilisant l'enveloppe pré-adressée et pré-affranchie fournie. Chaque questionnaire prend environ 10 à 20 minutes à compléter pour un total d'environ 1 heure à 1 heure et demie.

De plus, un(e) auxiliaire de recherche pourrait consulter le dossier médical de votre enfant afin d'obtenir des informations cliniques de base (diagnostic et durée de la maladie).

Confidentialité

Toute information recueillie au cours de cette étude demeurera complètement confidentielle. Votre nom et celui de votre enfant n'apparaîtra pas sur les questionnaires. Le médecin de votre enfant et tout autre professionnel de la santé à la clinique sera incapable de faire le lien entre vos réponses sur les questionnaires et vous ou votre enfant. Vous et votre enfant ne serez pas identifiés dans aucune publication qui pourrait résulter de cette étude.

Le Comité de Revue Interne (CRI) de l'hôpital de Montréal pour enfants pourrait prendre connaissance des données recueillies durant cette étude. Ceci est fait dans le but de s'assurer que les règles émises par le CRI sont respectées.

Bienfaits

Le fait de participer à cette étude n'apportera pas de bienfait direct à votre famille. Cependant, l'information que vous procurez aidera éventuellement les médecins et les thérapeutes à améliorer le traitement et la qualité de vie des enfants atteints d'Arthrite Juvénile Idiopathique.

Vous recevrez $10 pour couvrir les frais de transport et/ou de stationnement lors de la visite à la clinique au troisième mois de l'étude. De plus, pour chaque enveloppe que vous retournez, votre nom sera inclus dans un tirage. Cinq noms seront pigés au sort *chaque mois* et les gagnants recevront des prix d'une valeur de 10$.

Risques

Votre participation à cette étude ne comporte aucun risque prévisible pour vous ou votre famille.

Participation Volontaire

Votre participation à cette étude est volontaire. Vous êtes libres de refuser de répondre à n'importe quelle question, ou de refuser de participer ou de vous retirer de l'étude en tout temps. Ceci n'affectera pas le niveau des soins que votre enfant reçoit à l'hôpital de Montréal pour enfants.

Si vous avez des questions concernant vos droits en tant que patient(e) ou concernant toute plainte au sujet de cette étude, veuillez contacter Elisabeth Gibbon [redacted]. Si vous avez des questions portant sur cette étude, vous pouvez contacter Dr. Ciarán Duffy [redacted]

Déterminants des Résultats en Arthrite Juvénile Idiopathique

Consentement Libre et Éclairé (pour parents d'enfants atteints d'Arthrite Juvénile Idiopathique (AJI))

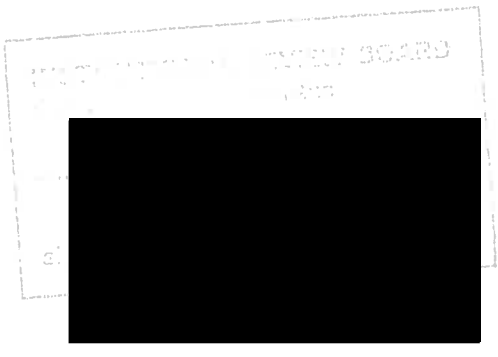
Je reconnais que les procédures de recherches, telles que décrites dans ce formulaire de consentement, m'ont été expliquées et que j'ai obtenu des réponses satisfaisantes à toutes mes questions. Je comprends que ma participation est volontaire. Je sais que j'ai le droit de me retirer de cette étude en tout temps, et ce, sans que le niveau des soins que reçoit mon enfant à l'hôpital de Montréal pour enfants soit compromis.

J'obtiendrai une copie du formulaire de consentement.

Les risques et inconforts possibles, ainsi que les bienfaits possibles de ma participation à cette étude m'ont été expliqués.

Toute information demeurera strictement confidentielle et l'anonymat de mon enfant sera protégé.

Nom du/de la participant(e)	Signature de l'enfant (si âgé(e) de plus de 7 ans)	Date (a/m/j)
Nom du parent / tuteur(trice)	Signature	Date (a/m/j)
Nom du témoin	Signature	Date (a/m/j)
Nom du chercheur	Signature	Date (a/m/j)



Centre universitaire de santé McGill
McGill University Health Centre

INFORMED CONSENT FORM (PARENT/GUARDIAN)

Title of the project : Comparison of the perceptions of children with juvenile arthritis and their parents regarding compliance to treatments and its impact on quality of life.

Names of investigators : Dr. Debbie Feldman and Dr. Ciarán Duffy

Objectives of the study : The goal of the study is to compare the perceptions of children with juvenile arthritis and their parents regarding compliance to treatments and its impact on quality of life.

Procedures : If you agree to have your child participate in this study, your child will be asked to complete one questionnaire about his/her quality of life and one questionnaire about compliance to treatments. These questions will be asked during one of your child's appointments at the clinic and the questionnaires will be administered by an occupational therapist who is also a masters student. The administration of the two questionnaires will take approximately 30 minutes. These questionnaires are two of the same ones that you complete within the context of the study regarding outcomes in juvenile arthritis.

Confidentiality : All information gathered during this study will be kept completely confidential. Your child's name will not appear on the questionnaire. Your child's physician and all other professionals at the clinic will not be able to link your answers or those of your child to you or your child. You and your child will not be identified in any publication which may result from this study.

Benefits : Participating in this study will have no direct benefit to your child and family. However, the information provided by you will eventually help physicians and therapists gain a better understanding of the perceptions of children with juvenile arthritis and their parents when speaking about compliance to treatments and its impact on quality of life to see if they are similar.

Risks : Participation in this study does not involve any foreseeable risks for you or your family.

Voluntary participation : Your participation in this study is strictly voluntary. You are free to refuse to participate or withdraw from the study at any time without having to justify your decision.

Authorization: I have read this consent form and I understand what I have read. I hereby certify that its consent was explained to me and that I have been given the opportunity to ask questions. I understand that I am free to refuse that my child participate or that he can withdraw from the study at any time without any prejudice to the treatment he receives at the clinic. I hereby certify that I have been given enough time to make a decision and I agree that my child participate in this study.

If you have any questions about your rights as a patient or any complaints about this study, please contact Elisabeth Gibbon at (514) 412-4400, extension 22223. If you have any questions about this study, please contact Dr. Ciarán Duffy at (514) 412-4400, extension 25232.

INSTITUTIONAL REVIEW BOARD
approved for 12 months
from date below
Feb 18/03
[redacted]

Signature of parent/guardian: Date:

Signature of witness: Date:

FORMULAIRE DE CONSENTEMENT ÉCLAIRÉ (PARENT/TUTEUR)

Titre du projet : Comparaison entre les perceptions des enfants atteints d'arthrite juvénile et de leurs parents en ce qui concerne le consentement aux traitements et son impact sur la qualité de vie.

Noms des chercheurs : Dre Debbie Feldman et Dr Ciarán Duffy.

Objectif de l'étude : Le but de cette étude est de comparer les perceptions des enfants atteints d'arthrite juvénile et de leurs parents en ce qui concerne le consentement aux traitements et l'impact sur la qualité de vie.

Procédures : Si vous acceptez que votre enfant participe à cette étude, il lui sera demandé de répondre aux questions d'un formulaire de qualité de vie et d'un formulaire de consentement aux traitements. Ces questionnaires seront administrés lors d'un des rendez-vous de votre enfant à la clinique par une ergothérapeute qui est aussi une étudiante à la maîtrise. La durée de la gestion des deux questionnaires sera d'environ 30 minutes. Ces deux questionnaires sont les mêmes que ceux auxquels vous avez répondu dans le contexte de l'étude sur les résultats de l'arthrite juvénile.

Confidentialité : Toute l'information recueillie au cours de cette étude est strictement confidentielle. Le nom de votre enfant ne sera pas indiqué sur le questionnaire. Le médecin de votre enfant et les autres professionnels travaillant à la clinique ne pourront pas établir de lien avec les réponses de vos questionnaires ni de celles de votre enfant. Ni vous ni votre enfant ne seront identifiés dans les publications pouvant découler de cette étude.

Bienfaits : Votre participation à cette étude n'apportera aucun bienfait direct à votre enfant et votre famille. Cependant, l'information recueillie permettra éventuellement aux médecins et thérapeutes de mieux comprendre les points de vue des enfants atteints d'arthrite juvénile et de leurs parents à propos du consentement et de la qualité de vie qui en découle afin de voir si ces points de vue sont identiques.

Risques : La participation à cette étude ne comporte aucun risque prévisible pour vous ou votre famille.

Participation volontaire : Votre participation est strictement volontaire. Vous pouvez refuser que de participer à cette étude ou d'interrompre la participation à tout moment sans avoir à justifier votre décision.

Autorisation : J'ai lu le formulaire de consentement et je comprends ce que j'ai lu. Je certifie que l'on m'a expliqué le contenu de ce formulaire et que j'ai eu l'occasion de poser des questions. Je comprends que je suis libre de refuser que mon enfant participe à cette étude ou d'interrompre sa participation à tout moment sans que cela n'affecte les traitements que mon enfant reçoit à la clinique. J'atteste par la présente que j'ai eu suffisamment de temps pour prendre une décision et j'accepte que mon enfant participe à cette étude.

Si vous avez des questions concernant vos droits en tant que patient(e) ou concernant toute plainte au sujet de cette étude, veuillez communiquer avec Elisabeth Gibbon au (514) 412-4400, poste 22223. Si vous avez des questions portant sur cette étude, veuillez joindre Dr Ciarán Duffy au (514) 412-4400, poste 25232.

FORMULAIRE DE CONSENTEMENT ÉCLAIRÉ (PARENT/TUTEUR)

Signature du parent/tuteur : Date :

Signature du témoin : Date :

INSTITUTIONAL REVIEW BOARD
approved for 12 months
from date below
March 14/03

[redacted]

Centre universitaire de santé McGill
McGill University Health Centre

ASSENT (CHILD)

Title of the project : Comparison of the perceptions of children with juvenile arthritis and their parents regarding compliance to treatments and its impact on quality of life.

Names of investigators : Dr. Debbie Feldman and Dr. Ciaran Duffy.

Objectives of the study : The goal of the study is to compare your perceptions and those of your parents about living with juvenile arthritis and about compliance with treatment (such as taking medications, doing exercises and wearing splints).

Procedures : If you agree to participate in this study, you will be asked to answer one questionnaire about your quality of life and another questionnaire about compliance to treatments (such as: how often you take medications, do your exercises and wear your splints). These questions will be asked during your appointment at the clinic and will take approximately 30 minutes.

Confidentiality : All information gathered during this study will be kept completely confidential. Your physician and all other professionals at the clinic will not be able to link your answers to you. You will not be identified in any publication which may result from this study.

Benefits : Participating in this study will have no direct benefit to you. However, the information provided by you will eventually help physicians and therapists gain a better understanding of the perceptions of children with juvenile arthritis and their parents when speaking about compliance to treatments and its impact on everyday life.

Risks : Participation in this study does not involve any foreseeable risks for you or your family.

Voluntary participation : Your participation in this study is strictly voluntary. You are free to refuse to participate or withdraw from the study at any time without having to justify your decision.

Authorization: I have read this consent form and I understand what I have read. I hereby certify that its consent was explained to me and that I have been given the opportunity to ask questions. I understand that I am free to refuse to participate or withdraw from the study at any time without any prejudice to the treatment I receive at the clinic. I hereby certify that I have been given enough time to make a decision and I agree to participate in this study.

INSTITUTIONAL REVIEW BOARD
approved for 12 months
from date 12/3/03

Signature of participant Date

Signature of witness Date

FORMULAIRE DE CONSENTEMENT ÉCLAIRÉ (ENFANT)

Titre du projet : Comparaison entre les perceptions des enfants atteints d'arthrite juvénile et de leurs parents en ce qui concerne le consentement aux traitements et son impact sur la qualité de vie.

Noms des chercheurs : Dre Debbie Feldman, Dr Ciarán Duffy.

Objectif de l'étude : Le but de cette étude est de comparer tes perceptions et celles de tes parents concernant l'arthrite juvénile et sur le consentement aux traitements (comme par exemple prendre tes médicaments, faire tes exercices et porter tes orthèses).

Procédures : Si tu acceptes de participer à cette étude, on te demandera de répondre à un questionnaire sur ta qualité de vie et un autre questionnaire concernant le consentement aux traitements (comme la fréquence à laquelle tu prends tes médicaments, fais tes exercices et utilises tes orthèses). Ces questions te seront posées lors de ton rendez-vous à la clinique et la durée de l'entrevue sera d'environ 30 minutes.

Confidentialité : Toute l'information recueillie au cours de cette étude est entièrement confidentielle. Ton médecin et les autres professionnels travaillant à la clinique ne pourront pas établir de lien entre tes réponses et toi. Si des articles sont écrits à la suite de cette étude, ton nom ne sera pas mentionné.

Bienfaits : Ta participation à cette étude ne t'apportera aucun bienfait direct. Cependant, l'information recueillie permettra éventuellement aux médecins et thérapeutes de mieux comprendre les points de vue des enfants atteints d'arthrite juvénile et de leurs parents à propos du consentement aux traitements et de son impact sur la vie de tous les jours.

Risques : Ta participation à cette étude ne comporte aucun risque prévisible pour toi ou ta famille.

Participation volontaire : Ta participation est strictement volontaire. Tu peux refuser de participer à cette étude ou arrêter d'y participer à tout moment sans avoir à justifier ta décision.

Autorisation : J'ai lu le formulaire de consentement et je comprends ce que j'ai lu. Je confirme que l'on m'a expliqué le contenu de ce formulaire et que j'ai eu l'occasion de poser des questions. Je comprends que je suis libre de refuser de participer à cette étude ou d'arrêter d'y participer à tout moment sans que cela n'affecte les traitements que je reçois à la clinique. Je certifie par la présente que j'ai eu suffisamment de temps pour prendre une décision et j'accepte de participer à cette étude.

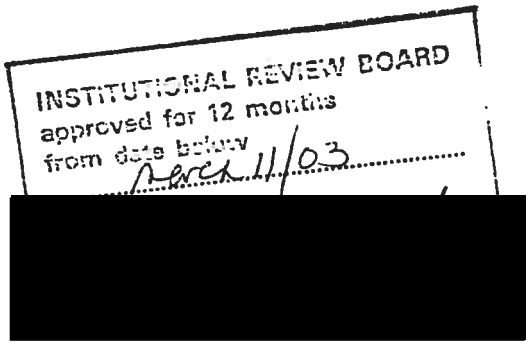
Si vous avez des questions concernant vos droits en tant que patient(e) ou concernant toute plainte au sujet de cette étude, veuillez communiquer avec Elisabeth Gibbon [redacted]. Si vous avez des questions portant sur cette étude, veuillez joindre Dr Ciarán Duffy [redacted],
[redacted]

FORMULAIRE DE CONSENTEMENT ÉCLAIRÉ (ENFANT)

Signature du participant : Date :

Signature du témoin : Date :

Signature du parent/tuteur : Date :



Centre universitaire de santé McGill
McGill University Health Centre

Informed Consent; Access to rehabilitation for children with physical disabilities

Groupe de recherche interdisciplinaire en santé (GRIS)
Université de Montréal
[redacted]

Principal Investigator :Dr. Debbie Feldman Montreal Children's Hospital
Université de Montréal
[redacted]

The Université de Montréal together with Hôpital Ste. Justine and the Montreal Children's Hospital is conducting a research study regarding rehabilitation services in Montreal for children with physical disabilities. The goal is to document waiting time, any problems with services, and to try to find strategies to improve accessibility and quality of rehabilitation services for children.

We ask that you complete one face-to-face interview, lasting about 30 minutes, regarding your experiences with respect to your family and your child's involvement in the rehabilitation process. An interviewer will contact you by telephone (15-minute interview), at 3 month intervals until your child is accepted at a rehabilitation centre, to ask you about any subsequent experiences with rehabilitation for your child. Although there is no direct benefit to your family, your experiences will enable review of this process with a goal towards improving availability and accessibility to services for children with physical disabilities. There is no risk whatsover to you or to your child.

You will not be identifiable from any publication resulting from this research study, nor will any data collected be traceable to you or your child. All information is strictly confidential.

Your participation is completely voluntary. You may refuse, at any time, to answer any question or withdraw from the study altogether, without any effect on your child's care.

Should you require any further information regarding the study, you may contact Dr. Debbie Feldman [redacted] You may also contact the hospital ombudsman Ms. Elisabeth Gibbon [redacted], to discuss any dissatisfaction with services or the study and with regard to questions concerning your rights as a research subject.

I agree to participate in this study :

Signature of parent/guardian _____ Signature of Investigator _____

Date _____ Date _____

MONTREAL CHILDREN'S HOSPITAL
OF THE MUHC
RESEARCH ETHICS BOARD
APPROVED FOR 12 MONTHS
[redacted]

INSTITUTIONAL REVIEW BOARD
approved for 12 months
from date below
25/02
[redacted]

L'HÔPITAL D[redacted]REN'S H
2300 rue T[redacted]

Centre universitaire de santé McGill
McGill University Health Centre

Accès aux services de réadaptation chez les enfants atteints d'une incapacité physique

Groupe de recherche interdisciplinaire en santé (GRIS)
Université de Montréal
[redacted]

Investigateur principal : D[r] Debbie Feldman Université de Montréal
Hôpital de Montréal pour Enfants [redacted]

L'Université de Montréal, en association avec l'Hôpital Ste-Justine et l'Hôpital de Montréal pour Enfants, réalise une étude sur les services de réadaptation à Montréal pour les enfants atteints d'incapacités physiques. Le but de notre recherche est de documenter les attentes, de cibler les problèmes pouvant survenir avec les services, et de trouver des stratégies pour améliorer l'accessibilité et la qualité des services de réadaptation destinés aux enfants.

Nous aimerions que vous répondiez à une entrevue individuelle, d'environ 30 minutes, portant sur vos expériences en tant que famille concernant le processus de réadaptation de votre enfant. Un interviewer communiquera avec vous par téléphone (entrevue de 15 minutes), à tous les trois mois, jusqu'à la prise en charge de votre enfant par le centre de réadaptation, afin de connaître vos expériences ultérieures avec les services de réadaptation de votre enfant. Bien qu'il n'y ait pas d'avantage immédiat pour votre famille, votre expérience nous permettra d'évaluer le processus avec l'objectif d'améliorer la disponibilité et l'accessibilité des services aux enfants atteints d'incapacités physiques. Il n'y a aucun risque pour vous ou votre enfant.

Vous ne serez pas identifié dans aucune publication découlant de ce projet de recherche et aucune données recueillies ne pourra vous retracer. Tous les renseignements demeurent strictement confidentiels. Votre participation est volontaire. Vous pouvez, à tout moment, refuser de répondre à une question ou décider de vous retirer de l'étude, sans subir de préjudice aux soins de votre enfant.

Si vous désirez avoir des renseignements supplémentaires vous pouvez communiquer avec le D[r] Debbie Feldman [redacted]. Vous pouvez aussi communiquer avec la protectrice des malades, Mme Elisabeth Gibbon [redacted] si vous n'êtes pas satisfait des services ou de l'étude et concernant vos droits en tant que sujet participant à une étude.

Je consens à participer à cette étude

Signature du parent/tuteur

Date

Signature du che[redacted]

Date

MONTREAL CHILDREN'S HOSPITAL
OF THE MUHC
RESEARCH ETHICS BOARD
APPROVED FOR 12 MONTHS
FROM: Apr. 20/04
[redacted]

HÔPITAL
SAINTE-JUSTINE
Le centre hospitalier universitaire mère-enfant

FORMULAIRE D'INFORMATION ET DE CONSENTEMENT

1. Titre de l'étude

Impact du délai de transfert vers les services de réadaptation chez les enfants présentant des problèmes de développement

2. Nom des chercheurs

Ce projet est dirigé par Debbie Feldman Ph.D. chercheure adjointe, du Groupe de recherche interdisciplinaire en santé à l'Université de Montréal. Il implique également l'étroite collaboration des chercheurs suivants : Julie Gosselin Ph.D., Bonnie Swaine Ph.D., François Champagne Ph.D. et Raynald Pineault Ph.D.

3. Source de financement

Cette étude reçoit le soutien financier du Fonds de la recherche en santé du Québec.

4. Invitation à participer à un projet de recherche

Le Groupe de recherche interdisciplinaire en santé, en collaboration avec l'Hôpital Ste-Justine et l'Hôpital Montréal pour Enfants, réalise une étude sur l'impact des délais d'attente pour l'obtention de services en réadaptation chez les enfants présentant des problèmes de développement. Nous sollicitons la participation de votre enfant. Nous vous invitons à lire ce formulaire d'information afin de décider si vous êtes intéressé(e) à ce que votre enfant participe à cette étude.

5. Quelle est la nature de ce projet ?

Votre enfant présente des problèmes de développement pour lesquels votre médecin vous a référé en réadaptation (ergothérapie et/ou physiothérapie). Le but de notre recherche est de mieux comprendre la situation actuelle dans les délais de transfert vers les services de réadaptation. Une meilleure compréhension des facteurs qui influencent ces délais devrait permettre de développer des stratégies pour faciliter l'accessibilité à de tels services et, éventuellement, à en améliorer la qualité. Pour ce faire, nous comptons recruter entre 400 et 450 enfants ayant bénéficié d'une évaluation médicale ayant mené à une référence en réadaptation. Ces enfants auront dû être évalués à l'Hôpital Montréal pour enfants ou encore à l'Hôpital Sainte-Justine.

6. Comment se déroulera le projet ?

L'étude comporte deux volets. Le premier volet vise à documenter le délai de transfert et les facteurs qui ont pu l'influencer. Il nécessitera la consultation des banques de données pour le suivi des soins de votre enfant au Service de réadaptation de l'Hôpital Sainte-Justine. Il faudra également consulter le dossier médical de votre enfant afin d'obtenir des informations le concernant qui sont pertinentes au projet de recherche (la date de référence, la date de premier rendez-vous avec un thérapeute et l'information sur les besoins de votre enfant). Le second volet vise à mieux comprendre votre situation durant cette période d'attente et impliquera des entrevues. La première entrevue sera faite à l'intérieur des 15 jours suivant la référence au centre de réadaptation et sera réalisée de façon directe en face-à-face. Les autres entrevues seront complétées par téléphone chaque trois mois jusqu'au moment du premier rendez-vous au centre de réadaptation. La première entrevue servira à recueillir des données concernant votre manière de gérer la situation d'attente, vos initiatives pour prendre en charge votre situation, le fonctionnement global de votre enfant ainsi que votre situation familiale. Les autres entrevues permettront de réévaluer les mêmes aspects auxquels s'ajouteront votre niveau de satisfaction face au

transfert incluant l'utilisation de services privés, les problèmes vécus en rapport avec le système et des suggestions pour améliorer la situation. Chaque entrevue durera approximativement 45 minutes et pourra être complétée au moment de la journée qui vous convient le mieux.

7. Quels sont les avantages et bénéfices ?

Cette étude n'aura aucun bénéfice direct sur la santé de votre enfant puisque nous n'analyserons que les facteurs influençant les délais d'attente pour obtenir des services en réadaptation. Les entrevues ne pourront pas servir à accélérer le processus de prise en charge de votre enfant en réadaptation. Il n'en demeure pas moins que votre participation à cette étude permettra d'améliorer les connaissances et éventuellement les services de réadaptation requis par des enfants comme le vôtre.

8. Quels sont les inconvénients et les risques ?

Cette étude ne comporte aucun risque pour votre enfant ou vous-même. Néanmoins, comme cette étude implique au moins deux entrevues, vous devrez être disponible à ces deux moments. Ces entrevues seront faites selon vos disponibilités afin de créer un minimum d'inconvénients pour vous. Il est important de rappeler que certains critères devront néanmoins être respectés (à l'intérieur des 15 jours suivant la demande de transfert et ensuite à chaque 3 mois suivant cette demande jusqu'au moment du premier rendez-vous au centre de réadaptation).

9. Comment la confidentialité est-elle assurée ?

Les données recueillies seront gardées dans une filière informatique sous un code numérique. Cependant, aux fins de vérifier la saine gestion de la recherche, il est possible qu'un délégué du comité d'éthique de la recherche et des organismes commanditaires consultent les données de recherche et le dossier médical de votre enfant. Par ailleurs, les résultats de cette étude pourront être publiés et communiqués dans un congrès scientifique mais aucune

information pouvant identifier votre enfant ne sera alors dévoilée. De fait, tous les renseignements obtenus sur votre enfant dans le cadre de ce projet de recherche demeureront confidentiels, à moins d'une autorisation de votre part ou d'une exception à la loi.

10. Responsabilité des chercheurs

En signant ce formulaire de consentement, vous ne renoncez à aucun de vos droits prévus par la loi ni à ceux de votre enfant. De plus, vous ne libérez pas les investigateurs de leur responsabilité légale et professionnelle advenant une situation qui causerait préjudice à votre enfant.

11. Y a-t-il une compensation prévue pour vos dépenses et inconvénients ?

Aucune compensation financière n'a été prévue.

12. Liberté de participation

La participation de votre enfant est volontaire. Toute nouvelle connaissance susceptible de remettre en question sa participation vous sera communiquée. Si vous choisissez de ne pas faire participer votre enfant ou de le retirer de l'étude, ce sera évidemment sans aucun préjudice pour les soins apportés à votre enfant.

13. En cas de questions ou de difficultés, avec qui peut-on communiquer ?

Pour plus d'information concernant cette recherche, contactez le chercheur responsable de cette étude, Dre Debbie Feldman à (514) 343-6111, poste 3141. Pour tout renseignement sur les droits de votre enfant à titre de participant à ce projet de recherche, vous pouvez contacter la conseillère à la clientèle de l'Hôpital Ste-Justine au (514) 345-4749.

14. Consentement

On m'a expliqué la nature et le déroulement du projet de recherche. J'ai pris connaissance du formulaire de consentement et on m'en a remis un exemplaire. J'ai eu l'occasion de poser des questions auxquelles on a répondu. Après réflexion, j'accepte que mon enfant participe à ce projet de recherche. J'autorise l'équipe de recherche à consulter le dossier médical de mon enfant et les informations le concernant qui sont conservées dans les banques de données de l'Hôpital Sainte-Justine pour obtenir les informations pertinentes à ce projet.

_____

Nom de l'enfant (Lettres moulées)

_____

Nom du parent (Lettres moulées)

_____ _____

Consentement du parent, tuteur (Signature) Date

15. Formule d'engagement du chercheur ou de la personne qu'il a déléguée

Le projet de recherche a été décrit au participant et/ou à son parent/tuteur ainsi que les modalités de la participation. Un membre de l'équipe de recherche (chercheur ou infirmière de recherche) a répondu à leurs questions et leur a expliqué que la participation au projet de recherche est libre et volontaire. L'équipe de recherche s'engage à respecter ce qui a été convenu dans le formulaire de consentement.

_____ _____

Signature du chercheur/délégué qui a obtenu le consentement Date

_____ _____

Nom du chercheur ou du délégué et fonction (Lettres moulées) Date

APPENDIX III: Background Study Questionnaire for Parents of Children with JIA

Project: JIA Study I
Form: GENINFO
MCH ID: _____
Date: ____ /____/____
dd mm yy

---

1. Age of child's mother: _____

2. Age of child's father: _____

3. Education of child's mother :
   - ❒ High school not completed
   - ❒ High school completed
   - ❒ CEGEP/College
   - ❒ University

4. Education of child's father :
   - ❒ High school not completed
   - ❒ High school completed
   - ❒ CEGEP/College
   - ❒ University

5. With whom does your child live ?
   - ❒ Both parents ❒ Mother only ❒ Father only
   - ❒ Shared custody ❒ Grandparent ❒ Other

6. How long has your child lived with the person(s) identified in Question 5? ____

7. What is your child's cultural background?
   - ❒ French Canadian ❒ English Canadian ❒ Haitian/Caribbean ❒ African
   - ❒ European ❒ Asian ❒ Mexican/Central American/South American
   - ❒ North African/Middle-Eastern ❒ Other: _____

8. What is the child's mother's current work status?
   - ❒ Employed full-time ❒ Employed part-time ❒ Student ❒ Retired
   - ❒ Disabled ❒ Unemployed (please specify for how long): _____
   - ❒ Other (please specify): _____

9. Is the child's mother receiving welfare? ❒ No ❒ Yes (please specify for how long): ____

10. What is the child's father's work status?
    - ❒ Employed full-time ❒ Employed part-time ❒ Student ❒ Retired
    - ❒ Disabled ❒ Unemployed (please specify for how long): ____
    - ❒ Other (please specify): _____

11. Is the child's father receiving welfare? ❒ No ❒ Yes (please specify for how long): _____

12. What is your best estimate of your current annual household before deductions (include income from all sources)

    - ❒ less than 14,999$ ❒ 15,000$ – 24,999$ ❒ 25,000$ – 34,999$ ❒ 35,000$ – 44,999$
    - ❒ 45,000$ – 54,999$ ❒ 55,000$ – 64,999$ ❒ 65,000$ – 74,999$ ❒ 75,000$ – 84,999$
    - ❒ 85,000$ – 94,999$ ❒ more than 95,000$

Thank you for your help with this study.

rojet: JIA Étude I
Formulaire: GENINFO
No. d'identification MCH: _____
Date:____/____/____
jj mm aa

---

1. Âge de la mère: ____

2. Âge du père: ____

3. Éducation de la mère de l'énfant:
   - ☐ École secondaire non completée
   - ☐ École secondaire completée
   - ☐ CEGEP/College
   - ☐ Université

4. Éducation du père de l'enfant:
   - ☐ École secondaire non completée
   - ☐ École secondaire completée
   - ☐ CEGEP/College
   - ☐ Université

5. Avec quelle personne(s) l'enfant habite-t-il?
   - ☐ Ses deux parents
   - ☐ Mère seule
   - ☐ Père seul
   - ☐ Garde partagée
   - ☐ Grandparent(s)
   - ☐ Autre

6. Depuis combien de temps l'enfant habite-t-il avec la/les personne(s) identifiée(s) à la question 5? ____

7. Quelle est l'origine culturelle de votre enfant?
   - ☐ Canadien Français
   - ☐ Canadien Anglais
   - ☐ Haitien/des Carraibes
   - ☐ Africain
   - ☐ Européen
   - ☐ Asiatique
   - ☐ Mexicain/d'Amérique Centrale ou du Sud
   - ☐ Autre:_____

8. Quel est la situation actuelle d'emploi de la mère de l'enfant?
   - ☐ Emploi temps plein
   - ☐ Emploi temps partiel
   - ☐ Étudiant(e)
   - ☐ Retraité(e)
   - ☐ Congé de maladie/handicapé
   - ☐ Sans emploi: Veuillez spécifier depuis combien de temps: ___
   - ☐ Autre: _____

9. Est-ce que la mère de l'enfant reçoit actuellement des prestations du bien-être social? ☐ Non ☐ Oui
   (Si "Oui", veuillez spécifier depuis combien de temps): _____

10. Quelle est la situation actuelle d'emploi du père de l'enfant?
    - ☐ Emploi temps plein
    - ☐ Emploi temps partiel
    - ☐ Étudiant
    - ☐ Retraité
    - ☐ Congé de maladie/handicapé
    - ☐ Sans emploi: Veuillez spécifier depuis combien de temps: ____
    - ☐ Autre: _____

11. Est-ce que le père de l'enfant reçoit actuellement des prestations du bien-être social? ☐ Non ☐ Oui
    (Si "Oui", veuillez spécifier depuis combien de temps): _____

12. Selon vous, quel est votre revenu familial annuel avant déduction (comptez vos revenus de toutes provenances)

    - ☐ moins de 14,999$
    - ☐ 15,000$ à 24,999$
    - ☐ 25,000$ à 34,999$
    - ☐ 35,000$ à 44,999$
    - ☐ 45,000$ à 54,999$
    - ☐ 55,000$ à 64,999$
    - ☐ 65,000$ à 74,999$
    - ☐ 75,000$ à 84,999$
    - ☐ 85,000$ à 94,999$
    - ☐ plus de 95,000$

Merci de votre participation à cette étude.

APPENDIX IV: Baseline Study Questionnaire for Parents of Children with PD

Name:
MCH/HSJ ID:
Date:____/____/
dd mm yy

INTERVIEW 1: QUESTIONNAIRE FACE TO FACE

PERSONAL DATA QUESTIONS: ***Now, I will ask you some general questions.***

1. In what area of town do you live (if living in Montreal, ask which district)?

   _____

2. What is your child's diagnosis?_____
3. When was your child diagnosed?_____
4. What is your child's date of birth?_____
5. What language does your child speak (if any)? _____
6. What language(s) does your child understand?_____
7. What language(s) do you speak?_____
8. Would you prefer to receive services for your child in English or French? _____
9. Which parent (s) is/are the usual caregiver(s) for the child?_____
10. Who else is involved in caring for your child?_____
11. What is the highest grade of school you have completed?

    some high school or less

    secondary V (finished high school)

    DEC (finished CEGEP)

    university degree, specify_____

    professional or graduate degree

Name:
MCH/HSJ ID:
Date:____/____/
dd mm yy

12. Ethnic origin:

☐ Canadian	☐ Canadian-French	☐ British Isles
☐ French	☐ South American	☐ Caribbean
☐ Aboriginal	☐ East and Southeast Asian	☐ Arab origins
☐ South Asian	☐ African	☐ other: _____

13. What income range best corresponds to the **combined income (before taxes)** for the household?

☐ 0-$19,999 ☐ $20,000-$39,999 ☐ $40,000-$59,000
☐ $60,000-$79,000 ☐ $80,000 and above

14. Who lives with your child? _____
15. Which of the following best describes your relationship to your child?

Biological parent	Step parent	Foster parent
Adoptive parent	Guardian	Other, please explain _____

16. Are you : male female
17. How many children do you have? _____

If you have other children:

18. How many are older than this child? _____
19. How many are younger than this child? _____
20. Which of the following best describes your current work status? (check all that apply)
    not working due to my child's health
    not working for other reasons
    looking for work outside the home
    working full or part time (either outside the home or at a home-based business)
    full time homemaker
21. If you are currently working what type of care arrangement are you using? You may choose more than one.
    daycare
    at home with a family member
    sitter at home
    family day care
    old enough to stay alone

Name:
MCH/HSJ ID:
Date:____/____/
dd mm yy

22. Did you have or are you having difficulties finding care arrangementfor your child?

Yes

No

23. If yes, what type of difficulties have you had? (ex. refuse integration, health problem too demanding etc.)

_____

_____

_____

_____

24. Who referred you to the rehabilitation services?_____

25. What do you think is a reasonable amount of time to wait for rehabilitation services, after having been referred by the doctor?

---

26. Rehabilitation Services: (interviewer asks the following questions and completes table)

* Which of the following services has your child ever received ?
(See table below)

* If your child has received services,

a) where did you receive them?
b) did you pay for these services privately?
c) estimate how often you received them

Name:
MCH/HSJ ID:
Date:____/____/
dd mm yy

	Occupational Therapy	Physical Therapy	Speech Language Pathology	Psychology	Special Education
Services received (if yes, answer below)					
Location of services:					
1. hospital					
2. rehab. center					
3. community					
4. day care					
5. home					
6. other					
Public (√) or Private ($):					
Frequency of services: *					
Duration of services Or Beginning date					

- 1=weekly, 2=biweekly (every two weeks), 3=monthly, 4=consultation only, 5=other.

Name:
MCH/HSJ ID:
Date:____/____/
dd mm yy

27. In the past, have you consulted other therapist to help your child's problem?

28. Which of the following Treatments have you ever used for your child's problems in the past? Please indicate the **type** of treatment your child received, **how often** you used this treatment, **who paid** for it, and how much it **helped** to improve your child's arthritis (please use the scale below to rate from 1 to 4 the level of improvement you observed as a result of treatment):

1 = No improvement
2 = Slight improvement
3 = Moderate improvement
4 = Much improvement

Type of treatment	**Number of visits or use <u>in the past</u>**	**Who paid for it?** *(i.e.,yourself, medicare, private insurance, free)*	**How much did this treatment help improve your child's condition?** *(use the above scale 1 to 4)*
Chiropractor			
Acupuncturist			
Osteopath			
Massage therapist			
Homeopath			
Naturopath *(herbal medicine)*			
Hypnotherapist			
Reflexologist			
Spiritual healer			
Dietary changes *(special diets, vitamins)*			
Folk remedies *(specify)* _____			
Other (specify): _____			

Name:
MCH/HSJ ID:
Date:____/____/
dd mm yy

29. Do you have any other comments on the subject of your child's rehabilitation services?

_____

_____

_____

_____

_____

Thank you for participating in our survey.

Nom :

MCH/SJH # d'identification : _____

Date:_____/_____/____

jj mm aa

ENTREVUE 1: QUESTIONNAIRE POST-RÉFÉRENCE: Face à face

RENSEIGNEMENTS PERSONNELS: ***Maintenant, je vais vous poser des questions générales concernant votre enfant et vous.***

1. Dans quelle municipalité (ou région de la ville) demeurez vous?

_____

2. Quel est le diagnostic de votre enfant?

_____

3. Quand votre enfant a-t-il été diagnostiqué? _____
4. Quelle est la date de naissance de votre enfant? _____
5. Quelles langues parle votre enfant? _____
6. Quelles langues votre enfant comprend-il?_____
7. Quelles langues parlez-vous?_____
8. Préféreriez-vous recevoir des services en anglais ou en français ? _____
9. Quel parent s'occupe habituellement des soins de votre enfant? _____
10. Qui d'autre est impliqué dans les soins pour votre enfant?

_____

11. Quel est le plus haut niveau de scolarité que vous ayez complété?

secondaire non terminé

secondaire 5 (terminé)

DEC (CEGEP terminé)

Diplôme universitaire, spécifié _____

Diplôme professionnel ou études graduées

12. Quelle est voitre origine ethnique:

☐ Canadienne	☐ Canadienne française	☐ Îles britanniques
☐ Fran□çaise	☐ Sud-Américaine	☐ Caraibes
☐ Aborigène	☐ Asie de l'est et du sud-est	☐ Origines arabes
☐ Sud-asiatique	☐ Africaine	☐ autre: _____

13. Parmi les choix suivant, lequel déçcrit le mieux votre revenu familial brut.

☐ 0-$19,999	☐ $20,000-$39,999	☐ $40,000-$59,000
☐ $60,000-$79,000	☐ $80,000 and above	

14. Qui vit avec votre enfant?

_____

15. Lequel parmi ces énoncés décrit le mieux votre lien avec votre enfant?

Parent biologique	Beau parent	Famille d'accueil
Parent adoptif	Tuteur	Autre, svp expliquer

16. Vous êtes : homme femme
17. Combien d'enfants avez-vous ? _____

Si vous avez d'autres enfants:

18. Combien sont plus âgés que cet enfant ?_____
19. Combien sont plus jeunes que cet enfant?____ _____
20. Lequel de ces énoncés décrit le mieux votre statut d'emploi actuel? Vous pouvez en cocher plus d'un.

    Sans emploi en raison de la santé de mon enfant.
    Sans emploi pour d'autres raisons.
    À la recherche d'un emploi à l'extérieur de la maison.
    Emploi à temps plein ou partiel (à l'extérieur ou entreprise à la maison)
    À la maison à temps plein

21. Si vous avez un emploi quel genre de type d'arrangement de garde utilisez-vous? Vous pouvez en cocher plus d'un.

    garderie
    à la maison avec un membre de la famille
    gardienne à la maison
    garderie en milieu familial
    assez vieux pour rester seul

22. Avez vous eu de la difficulté ou avez-vous de la difficulté à trouver un arrangement pour garder vos enfants?

Oui

Non

23. Si oui, quelles ont été ou sont les difficultés rencontrées? (ex. refuse l'intégration, problème de santé trop lourd etc.)

_____

_____

_____

_____

24. Qui vous a référé aux services de réadaptation (ergothérapie ou physiothérapie)?

_____

25. Selon vous, quel serait un délai d'attente raisonnable pour recevoir des services de réadaptation suite à une référence du médecin?

_____

26. Votre enfant a-t-il déjà reçu des services de réadaptation, si oui, lesquels parmi les suivants

NON, mon enfant a reçu aucun service.

	Ergothérapie	Physiothérapie	orthophonie	Psychologie	Éducation spécialisée
Services reçus					
Emplacement des services:					
1. hôpital					
2. centre de réadaptation					
3. services communautaires					
4. garderie					
5. à la maison					
6. autre					
Publique (√) ou Privé ($):					
Fréquencedes services: *					
Durée des services Ou date de début					

* 1=hebdomadaire, 2= tous les 2 semaines 3=1 X par mois, 4=consultation seulement, 5=autre.

27. Dans le passé, avez-vous consulté d'autres thérapeutes pour aider le problème de votre enfant.

❒ Oui ❒ Non

28. Quel autre type de thérapie avez-vous consulté? SVP veuillez indiquer le type de traitement, la fréquence des traitements, qui a payé pour ces services, et indiquez comment ce traitement a aidé la condition de votre enfant (veuillez utiliser l'échelle ci-dessous):

1 = pas d'amélioration

2 = un peu d'amélioration

3 = amélioration modérée

4 = beaucoup d'amélioration

Type de traitement	**Nombre de visites au cours des 3 derniers mois**	**Qui a payé?** *(i.e.,vous, RAMQ, assurance privée, gratuit)*	**Dans quelle mesure ce traitement a-t-il aidé la condition de votre enfant?** *(voir échelle ci-haut)*
Chiropractie			
Acupuncture			
Ostéopathie			
Massothérapie			
Homéopathie			
Naturopathie			
Hypnothérapie			
Réflexologie			
Guérisseur			
Diète spéciale			
Autre (spécifié): _____			

29. Avez-vous d'autres commentaires au sujet des services de réadaptation de votre enfant ?

_____

_____

_____

_____

_____

_____

Merci de votre collaboration à notre étude.

APPENDIX V: CHIP

Project: JIA Study I
Form: CHIPKID_6M
MCH ID: _____
Date:____ ____/___
dd mm yy

DIRECTIONS: To complete this inventory you are asked to read the list of "Coping Behaviors" below, one at a time.
For each coping behavior you used in the past month, please record how helpful it was. Circle ONE number:

3 = Extremely helpful
2 = Moderately helpful
1 = Minimally helpful
0 = Not helpful

For each coping behavior you did *not* use please record your reason by checking (√) *one* of the boxes: "Chose not to use it" or "Not possible".

Please begin: Please read and record your decision for EACH and EVERY coping behavior listed below.

						Not Used Reasons	
	COPING BEHAVIORS	**Extremely helpful**	**Moderately helpful**	**Minimally helpful**	**Not helpful**	**Chose not to**	**Not possible**
1.	Trying to maintain family stability	3	2	1	0		
2.	Engaging in relationships and friendships which help me to feel important and appreciated	3	2	1	0		
3.	Trusting my spouse (or former spouse) to help support me and my child(ren)	3	2	1	0		
4.	Sleeping	3	2	1	0		
5.	Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center	3	2	1	0		
6.	Believing that my child(ren) will get better	3	2	1	0		

Form: CHIPKID_6M
MCH ID: _____

						Not Used Reasons	
	COPING BEHAVIORS	**Extremely helpful**	**Moderately helpful**	**Minimally helpful**	**Not helpful**	**Chose not to**	**Not possible**
7.	Working, outside employment	3	2	1	0		
8.	Showing that I am strong	3	2	1	0		
9.	Purchasing gifts for myself and/or other family members	3	2	1	0		
10.	Talking with other individuals/parents in my same situation	3	2	1	0		
11.	Taking good care of all the medical equipment at home	3	2	1	0		
12.	Eating	3	2	1	0		
13.	Getting other members of the family to help with chores and tasks at home	3	2	1	0		
14.	Getting away by myself	3	2	1	0		
15.	Talking with the doctor about my concerns about my child(ren) with the medical condition	3	2	1	0		
16.	Believing that the medical center/hospital has my family's best interest in mind	3	2	1	0		
17.	Building close relationships with people	3	2	1	0		
18.	Believing in God	3	2	1	0		
19.	Developing myself as a person	3	2	1	0		
20.	Talking with other parents in the same type of situation and learning about their experiences	3	2	1	0		

Form: CHIPKID_6M
MCH ID: _____

						Not Used Reasons	
	COPING BEHAVIORS	**Extremely helpful**	**Moderately helpful**	**Minimally helpful**	**Not helpful**	**Chose not to**	**Not possible**
21.	Doing things together as a family (involving all members of the family)	3	2	1	0		
22.	Investing time and energy in my job	3	2	1	0		
23.	Believing that my child is getting the best medical care possible	3	2	1	0		
24.	Entertaining friends in our home	3	2	1	0		
25.	Reading about how other persons in my situation handle things	3	2	1	0		
26.	Doing things with family relatives	3	2	1	0		
27.	Becoming more self-reliant and independent	3	2	1	0		
28.	Telling myself that I have many things I should be thankful for	3	2	1	0		
29.	Concentrating on hobbies (art, music, jogging, etc.)	3	2	1	0		
30.	Explaining our family situation to friends and neighbors so they will understand us	3	2	1	0		
31.	Encouraging child(ren) with medical condition to be more independent	3	2	1	0		
32.	Keeping myself in shape and well-groomed	3	2	1	0		

Form: CHIPKID_6M
MCH ID: _____

						Not Used Reasons	
	COPING BEHAVIORS	**Extremely helpful**	**Moderately helpful**	**Minimally helpful**	**Not helpful**	**Chose not to**	**Not possible**
33.	Involvement in social activities (parties, etc.) with friends	3	2	1	0		
34.	Going out with my spouse on a regular basis	3	2	1	0		
35.	Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis	3	2	1	0		
36.	Building a closer relationship with my spouse	3	2	1	0		
37.	Allowing myself to get angry	3	2	1	0		
38.	Investing myself in my child(ren)	3	2	1	0		
39.	Talking to someone (not professional counselor/doctor) about how I feel	3	2	1	0		
40.	Reading more about the medical problem which concerns me	3	2	1	0		
41.	Talking over personal feelings and concerns with spouse	3	2	1	0		
42.	Being able to get away from the home care tasks and responsibilities for some relief	3	2	1	0		
43.	Having my child with the medical condition seen at the clinic/hospital on a regular basis	3	2	1	0		
44.	Believing that things will always work out	3	2	1	0		
45.	Doing things with my children	3	2	1	0		

Projet: JIA Étude I
Formulaire: CHIPKID
No. d'identification MCH: _____
Date:____/____/_____
jj mm aa

DIRECTIVES: Pour compléter l'inventaire, vous devez lire un à un les "moyens de faire face" présentés ci-dessous. Ces moyens font référence aux efforts reliés à la gestion de la vie familiale chez les parents qui ont un enfant souffrant d'une maladie chronique.
Pour chacun des moyens utilisés, veuillez indiquer dans quelle mesure il a été utile en encerclant un chiffre.

3 = Extrêmement utile
2 = Modérément utile
1 = Utile de façon minimale
0 = Pas utile

Pour chacun moyen que vous n'avez *pas* utilisés, veuillez indiquez votre raison en cochant (√) l'*une* des cases: "Décider de ne pas l'utiliser" ou "Pas possible".

Veuillez commencer: Veuillez lire et indiquer votre décision pour CHAQUE moyen énuméré ci-dessous.

						Moyens non utilisés/Raisons	
	MOYENS DE FAIRE FACE	**Extrêmement utile**	**Modérément utile**	**Utile de façon minimale**	**Pas utile**	**Décider de ne utiliser**	**Pas possible**
1.	Tenter de maintenir la stabilité familiale	3	2	1	0		
2.	M'engager dans des amitiés et d'autres relations m'aidant à me sentir important(e) et apprécié(e)	3	2	1	0		
3.	Faire confiance à mon époux(se) (ou ex-époux(se)) pour son aide de support envers moi et mon(mes) enfant(s)	3	2	1	0		
4.	Dormir	3	2	1	0		
5.	Discuter avec le personnel médical (infirmières, travailleur social, etc.) lors des visites à la clinique médicale	3	2	1	0		
6.	Croire que mes enfants iront mieux	3	2	1	0		

						Moyens non utilisés/Raisons	
	MOYENS DE FAIRE FACE	**Extrêmement utile**	**Modérément utile**	**Utile de façon minimale**	**Pas utile**	**Décider de ne utiliser**	**Pas possible**
7.	Travailler hors emploi	3	2	1	0		
8.	Montrer que je suis fort(e)	3	2	1	0		
9.	M'acheter des cadeaux et/ou en acheter à un autre membre de la famille	3	2	1	0		
10.	Parler avec d'autres individus/parents qui sont dans la même situation	3	2	1	0		
11.	Prendre bien soin de tout le matériel médical à la maison	3	2	1	0		
12.	Manger	3	2	1	0		
13.	Obtenir l'aide des autres membres de la famille pour les tâches ménagères	3	2	1	0		
14.	Prendre du temps pour moi-même à l'extérieur de la maison	3	2	1	0		
15.	Discuter avec le médecin de mes préoccupations concernant mon/mes enfant(s) malades	3	2	1	0		
16.	Croire que la clinique médicale/l'hôpital a à coeur l'intérêt de ma famille	3	2	1	0		
17.	Bâtir des relations profondes avec des gens	3	2	1	0		
18.	Croire en Dieu	3	2	1	0		
19.	Me développer comme individu	3	2	1	0		
20.	Parler et apprendre des expériences des parents qui sont dans le mêmes genre de situation	3	2	1	0		

						Moyens non utilisés/Raisons	
	MOYENS DE FAIRE FACE	**Extrêmement utile**	**Modérément utile**	**Utile de façon minimale**	**Pas utile**	**Décider de ne utiliser**	**Pas possible**
21.	Faire des choses en famille (impliquer tous les membres de la famille)	3	2	1	0		
22.	Investir temps et énergie dans mon travail	3	2	1	0		
23.	Croire que mon enfant reçoit les meilleurs soins médicaux possibles	3	2	1	0		
24.	Recevoir des amis à la maison	3	2	1	0		
25.	Lire sur la façon dont des personnes dans la même situation font face aux choses	3	2	1	0		
26.	Faire des choses avec les proches parents	3	2	1	0		
27.	Devenir plus autonome et indépendant(e)	3	2	1	0		
28.	Me dire qu'il y a plusieurs choses pour lesquelles je devrais être reconnaissant(e)	3	2	1	0		
29.	Me concentrer sur les passe-temps (art, musique, jogging, etc.)	3	2	1	0		
30.	Expliquer notre situation familialle aux amis et voisins pour les aider à nous comprendre	3	2	1	0		
31.	Encourager l'/les enfant(s) malade(s) à être plus indépendant(s)	3	2	1	0		
32.	Rester en forme et soigné(e)	3	2	1	0		

						Moyens non utilisés/Raisons	
	MOYENS DE FAIRE FACE	**Extrêmement utile**	**Modérément utile**	**Utile de façon minimale**	**Pas utile**	**Décider de ne utiliser**	**Pas possible**
33.	Participer à des activités sociales (soirées, etc.) avec des amis	3	2	1	0		
34.	Sortir régulièrement avec mon époux(se)	3	2	1	0		
35.	M'assurer que les traitements médicaux prescrits à mon/mes enfant(s) sont donnés tous les jours à la maison	3	2	1	0		
36.	Bâtir une relation plus solide avec mon époux(se)	3	2	1	0		
37.	Me permettre d'être fâché(e)	3	2	1	0		
38.	M'impliquer auprès de mon/mes enfant(s)	3	2	1	0		
39.	Parler avec quelqu'un (pas un thérapeute professionel/pas un médecin) de ce que je ressens	3	2	1	0		
40.	Lire plus sur le sujet médical qui me touche	3	2	1	0		
41.	Parler avec mon époux(se) de mes préoccupations et de mes émotions	3	2	1	0		
42.	Être capable de m'éloigner des soins donnés à la maison et des responsabilités pour avoir un peu de répit	3	2	1	0		
43.	Faire voir régulièrement mon enfant malade à la clinique médicale/l'hôpital	3	2	1	0		
44.	Croire que les choses vont toujours s'arranger	3	2	1	0		
45.	Faire des choses avec mes enfants	3	2	1	0		

APPENDIX VI: JAQQ

JUVENILE ARTHRITIS

QUALITY OF LIFE QUESTIONNAIRE

(JAQQ)

Ciarán M. Duffy, MB BCh MSc FRCPC

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JUVENILE ARTHRITIS

QUALITY OF LIFE QUESTIONNAIRE

(JAQQ-6M)

CONFIDENTIAL

Patient ID: _____ Date: _____ / _____ / _____
year month day

Name: _____

Address: _____

Phone #: _____

Age: _____ / _____ Date of birth: _____ / _____ / _____
year month year month day

Sex: _____ M/F

Diagnosis: _____

Duration of illness: _____

Interviewee: _____
(Relationship to patient)

Father's Occupation: _____

Mother's Occupation: _____

Language spoken most often: _____

FOR OFFICE USE ONLY

Score – Gross Motor: _____ Item Numbers: _____, _____, _____, _____, _____

Score – Fine Motor: _____ Item Numbers: _____, _____, _____, _____, _____

Score – Psychosocial: _____ Item Numbers: _____, _____, _____, _____, _____

Score – Symptoms: _____ Item Numbers: _____, _____, _____, _____, _____

Score – Pain: _____ Section Numbers: _____, _____, _____, _____, _____

SECTION 1 – GROSS MOTOR FUNCTION

A. How often have you/your child, over the past **2 WEEKS**, had difficulty with the following activities **AS A RESULT OF ARTHRITIS OR ITS TREATMENT**? Please score all items, numbered 1-17 below, in accordance with the following scale. Circle the number from 1-7 to the right of the item which corresponds with how often you/your child has had difficulty with this particular item.

If you/your child is unable to perform a particular activity because you/he/she is too young or would not be expected to perform this activity for any other reason, **please circle 0 – does not apply**.

SCORING SCALE

0 = Does not apply to me/my child

1 = None of the time	- NEVER
2 = Hardly any of the time	- 10% of the time
3 = Some of the time	- 25% of the time
4 = Half of the time	- 50 % of the time
5 = Most of the time	- 75% of the time
6 = Almost all of the time	- 90% of the time
7 = All of the time	- ALWAYS

1	Getting out of bed upon awakening	0	1	2	3	4	5	6	7
2	Stepping in and out of the shower or bath	0	1	2	3	4	5	6	7
3	Washing, combing or brushing hair	0	1	2	3	4	5	6	7
4	Putting on underwear, skirt or pants	0	1	2	3	4	5	6	7
5	Pulling on sweater or coat	0	1	2	3	4	5	6	7
6	Walking on a flat surface for ½ block or walking up a slight incline	0	1	2	3	4	5	6	7
7	Walking up or down a flight of 10 stairs	0	1	2	3	4	5	6	7
8	Running 2 blocks	0	1	2	3	4	5	6	7

SECTION 1 – GROSS MOTOR FUNCTION – cont'd.

SCORING SCALE

0 = Does not apply to me/my child

1 = None of the time	- NEVER
2 = Hardly any of the time	- 10% of the time
3 = Some of the time	- 25% of the time
4 = Half of the time	- 50 % of the time
5 = Most of the time	- 75% of the time
6 = Almost all of the time	- 90% of the time
7 = All of the time	- ALWAYS

9	Riding a bicycle (or tricycle)	0	1	2	3	4	5	6	7
10	Playing a favourite sport (Which one? _____)	0	1	2	3	4	5	6	7
11	Participating in physical education class	0	1	2	3	4	5	6	7
12	Bending and lifting an object from the floor	0	1	2	3	4	5	6	7
13	Kneeling, or sitting on heels for several minutes	0	1	2	3	4	5	6	7
14	Sitting for ½ hour	0	1	2	3	4	5	6	7
15	Turning to look over your shoulder	0	1	2	3	4	5	6	7
16	Chewing or swallowing food	0	1	2	3	4	5	6	7
17	Standing for ½ hour	0	1	2	3	4	5	6	7

B. From the above list of 17 items, please select the 5 items that are the biggest problem for your/your child, by circling the item number on the left. If you cannot identify 5, select as many as are relevant up to a maximum of 5.

SECTION 1 – GROSS MOTOR FUNCTION – cont'd.

C. If you/your child have any difficulties with any other similar physical activity that has not been mentioned, please describe it below and score the degree of difficulty using the same scale as above.

_____	1	2	3	4	5	6	7
_____	1	2	3	4	5	6	7
_____	1	2	3	4	5	6	7

SECTION 2 – FINE MOTOR FUNCTION

A. How often have you/your child, over the past **2 WEEKS**, had difficulty with the following activities **AS A RESULT OF ARTHRITIS OR ITS TREATMENT**? Please score all items, numbered 1-16 below, in accordance with the following scale. Circle the number from 1-7 to the right of the item which corresponds with how often you/your child has had difficulty with this particular item.

If you/your child is unable to perform a particular activity because you/he/she is too young or would not be expected to perform this activity for any other reason, **please circle 0 – does not apply**.

SCORING SCALE

0 = Does not apply to me/my child

1 = None of the time	- NEVER
2 = Hardly any of the time	- 10% of the time
3 = Some of the time	- 25% of the time
4 = Half of the time	- 50 % of the time
5 = Most of the time	- 75% of the time
6 = Almost all of the time	- 90% of the time
7 = All of the time	- ALWAYS

1	Turning the faucets (taps) on and off	0	1	2	3	4	5	6	7
2	Brushing teeth	0	1	2	3	4	5	6	7
3	Pulling on socks	0	1	2	3	4	5	6	7
4	Putting on shoes	0	1	2	3	4	5	6	7
5	Tying shoe laces	0	1	2	3	4	5	6	7
6	Putting on shirt/blouse	0	1	2	3	4	5	6	7
7	Fastening shirt or coat buttons	0	1	2	3	4	5	6	7
8	Putting on gloves	0	1	2	3	4	5	6	7

SECTION 2 – FINE MOTOR FUNCTION – cont'd.

SCORING SCALE

0 = Does not apply to me/my child

1 = None of the time	- NEVER
2 = Hardly any of the time	- 10% of the time
3 = Some of the time	- 25% of the time
4 = Half of the time	- 50 % of the time
5 = Most of the time	- 75% of the time
6 = Almost all of the time	- 90% of the time
7 = All of the time	- ALWAYS

9	Turning the handle to open the door	0	1	2	3	4	5	6	7
10	Opening a soft drink can	0	1	2	3	4	5	6	7
11	Twisting off a bottle/jar top (previously opened)	0	1	2	3	4	5	6	7
12	Lifting a cup and drinking from it	0	1	2	3	4	5	6	7
13	Using a spoon, knife or fork	0	1	2	3	4	5	6	7
14	Writing, drawing or colouring with a pencil/pen/crayon or painting with a small paintbrush	0	1	2	3	4	5	6	7
15	Using an eraser	0	1	2	3	4	5	6	7
16	Cutting paper with scissors	0	1	2	3	4	5	6	7

B. From the above list of 16 items, please select the 5 items that are the biggest problem for your/your child, by circling the item number on the left. If you cannot identify 5, select as many as are relevant up to a maximum of 5.

SECTION 2 – FINE MOTOR FUNCTION – cont'd.

C. If you/your child have any difficulties with any other similar fine motor physical activity that has not been mentioned, please describe it below and score the degree of difficulty using the same scale as above.

_____	1	2	3	4	5	6	7
_____	1	2	3	4	5	6	7
_____	1	2	3	4	5	6	7

SECTION 3 – PSYCOSOCIAL FUNCTION

A. How often have you/your child, over the past **2 WEEKS**, had difficulty with the following activities **AS A RESULT OF ARTHRITIS OR ITS TREATMENT**? Please score all items, numbered 1-22 below, in accordance with the following scale. Circle the number from 1-7 to the right of the item which corresponds with how often you/your child has had difficulty with this particular item.

If you/your child is unable to perform a particular activity because you/he/she is too young or would not be expected to perform this activity for any other reason, **please circle 0 – does not apply**.

SCORING SCALE

0 = Does not apply to me/my child

1 = None of the time	- NEVER
2 = Hardly any of the time	- 10% of the time
3 = Some of the time	- 25% of the time
4 = Half of the time	- 50 % of the time
5 = Most of the time	- 75% of the time
6 = Almost all of the time	- 90% of the time
7 = All of the time	- ALWAYS

1	Disobeyed or interacted poorly with parents	0	1	2	3	4	5	6	7
2	Interacted poorly with brothers or sisters	0	1	2	3	4	5	6	7
3	Interacted poorly with other children	0	1	2	3	4	5	6	7
4	Was mean to others	0	1	2	3	4	5	6	7
5	Hung around others who get into trouble	0	1	2	3	4	5	6	7
6	Argued a lot	0	1	2	3	4	5	6	7
7	Demanded a lot of attention	0	1	2	3	4	5	6	7
8	Got teased a lot	0	1	2	3	4	5	6	7

SECTION 3 – PSYCHOSOCIAL FUNCTION – cont'd.

SCORING SCALE

0 = Does not apply to me/my child

1 = None of the time	- NEVER
2 = Hardly any of the time	- 10% of the time
3 = Some of the time	- 25% of the time
4 = Half of the time	- 50 % of the time
5 = Most of the time	- 75% of the time
6 = Almost all of the time	- 90% of the time
7 = All of the time	- ALWAYS

9	Cried a lot for no apparent reason	0	1	2	3	4	5	6	7
10	Was easily jealous	0	1	2	3	4	5	6	7
11	Complained of loneliness	0	1	2	3	4	5	6	7
12	Felt unloved	0	1	2	3	4	5	6	7
13	Felt frustrated	0	1	2	3	4	5	6	7
14	Felt depressed	0	1	2	3	4	5	6	7
15	Felt worthless or inferior	0	1	2	3	4	5	6	7
16	Felt sad	0	1	2	3	4	5	6	7
17	Missed school (other than for appointments)	0	1	2	3	4	5	6	7
18	Disturbed the class at school	0	1	2	3	4	5	6	7
19	Couldn't pay attention for long	0	1	2	3	4	5	6	7

SECTION 3 – PSYCHOSOCIAL FUNCTION – cont'd.

SCORING SCALE

0 = Does not apply to me/my child

1 = None of the time	- NEVER
2 = Hardly any of the time	- 10% of the time
3 = Some of the time	- 25% of the time
4 = Half of the time	- 50 % of the time
5 = Most of the time	- 75% of the time
6 = Almost all of the time	- 90% of the time
7 = All of the time	- ALWAYS

---

20 Disobeyed teachers

0 1 2 3 4 5 6 7

21 Did poorly at school

0 1 2 3 4 5 6 7

22 Failed to finish things already started

0 1 2 3 4 5 6 7

B. From the above list of 22 items, please select the 5 items that are the biggest problem for your/your child, by circling the item number on the left. If you cannot identify 5, select as many as are relevant up to a maximum of 5.

C. If you/your child have exhibited any behaviour or mood that has not been mentioned, please describe it below and score the degree of difficulty using the same scale as above.

_____ 1 2 3 4 5 6 7

_____ 1 2 3 4 5 6 7

_____ 1 2 3 4 5 6 7

SECTION 4 – SYSTEMIC SYMPTOMS

A. How often have you/your child, over the past **2 WEEKS**, had difficulty with the following activities **AS A RESULT OF ARTHRITIS OR ITS TREATMENT**? Please score all items, numbered 1-19 below, in accordance with the following scale. Circle the number from 1-7 to the right of the item which corresponds with how often you/your child has had difficulty with this particular item.

If you/your child is unable to perform a particular activity because you/he/she is too young or would not be expected to perform this activity for any other reason, **please circle 0 – does not apply**.

SCORING SCALE

0 = Does not apply to me/my child

1 = None of the time	- NEVER
2 = Hardly any of the time	- 10% of the time
3 = Some of the time	- 25% of the time
4 = Half of the time	- 50 % of the time
5 = Most of the time	- 75% of the time
6 = Almost all of the time	- 90% of the time
7 = All of the time	- ALWAYS

1	Poor appetite	0	1	2	3	4	5	6	7
2	Mouth sores	0	1	2	3	4	5	6	7
3	Nausea/vomiting	0	1	2	3	4	5	6	7
4	Abdominal pain	0	1	2	3	4	5	6	7
5	Heartburn	0	1	2	3	4	5	6	7
6	Diarrhoea	0	1	2	3	4	5	6	7
7	Constipation	0	1	2	3	4	5	6	7
8	Blood on stool (Blood with bowel movement)	0	1	2	3	4	5	6	7

SECTION 4 – SYSTEMIC SYMPTOMS – cont'd.

SCORING SCALE

0 = Does not apply to me/my child

1 = None of the time	- NEVER
2 = Hardly any of the time	- 10% of the time
3 = Some of the time	- 25% of the time
4 = Half of the time	- 50 % of the time
5 = Most of the time	- 75% of the time
6 = Almost all of the time	- 90% of the time
7 = All of the time	- ALWAYS

9	Sore, painful, red eyes	0	1	2	3	4	5	6	7
10	Skin rash	0	1	2	3	4	5	6	7
11	Pain or discomfort passing urine	0	1	2	3	4	5	6	7
12	Dark or blood stained urine	0	1	2	3	4	5	6	7
13	Headache	0	1	2	3	4	5	6	7
14	Fever	0	1	2	3	4	5	6	7
15	Decreased or limited strength	0	1	2	3	4	5	6	7
16	Stiffness	0	1	2	3	4	5	6	7
17	Tires easily	0	1	2	3	4	5	6	7
18	Joint swelling	0	1	2	3	4	5	6	7
19	Joint tenderness or pain	0	1	2	3	4	5	6	7

SECTION 4 – SYSTEMIC SYMPTOMS – cont'd.

SCORING SCALE

0 = Does not apply to me/my child

1 = None of the time	- NEVER
2 = Hardly any of the time	- 10% of the time
3 = Some of the time	- 25% of the time
4 = Half of the time	- 50 % of the time
5 = Most of the time	- 75% of the time
6 = Almost all of the time	- 90% of the time
7 = All of the time	- ALWAYS

B. From the above list of 19 items, please select the 5 items that are the biggest problem for your/your child, by circling the item number on the left. If you cannot identify 5, select as many as are relevant up to a maximum of 5.

C. If you/your child have any symptom or problem that has not been mentioned, please describe it below and score the degree of difficulty using the same scale as above.

_____	_____
	1 2 3 4 5 6 7
_____	_____
	1 2 3 4 5 6 7
_____	_____
	1 2 3 4 5 6 7

SECTION 5 – PAIN ASSESSMENT

1. **Patient/Parent's impression of patient's pain :**

   a) Mark an x on the line at a point corresponding to your degree of pain overall in the past week

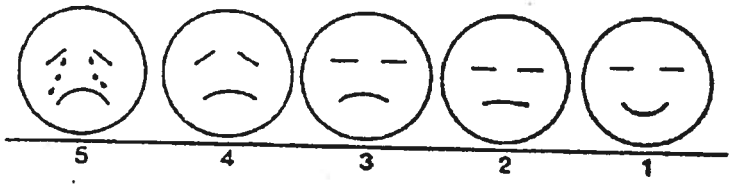
   (0 = no pain; 10 = worst pain imaginable)

   0 _____ 10

   b) Which of these phrases would you use to describe your child's (your) pain (overall in the past week)? Please circle one.

   no pain slight pain moderate pain severe pain extreme pain

   c) If your child is 10 years or younger, please ask your child to select the picture which best corresponds with his/her degree of pain (overall in the past week):



2. **Patient/Parent global assessment:** Relative to the last assessment do you feel your child is:

   1) Much better 2) Better 3) Same 4) Worse 5) Much worse

L'ARTHRITE JUVÉNILE

LA QUALITÉ DE VIE – QUESTIONNAIRE

(JAQQ)

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et
Louise Arsenault

Divisions de Rhumatologie et Recherche communautaire, Développement et Épidémiologique, Département de Pédiatrie, L'Hôpital de Montréal pour Enfants et l'Université de McGill

QUESTIONNAIRE

L'ARTHRITE JUVÉNILE ET LA QUALITÉ DE VIE (JAQQ-6M)

CONFIDENTIEL

N° d'identification : _____ Date : _____ / _____ / _____
année mois jour

Nom : _____

Adresse: _____

Téléphone : _____

Age : _____ /_____ Date de naissance : _____ / _____ / _____
ans mois

Sexe : _____ M/F

Diagnostic: _____

Diagnostiqué depuis : _____

Personne interrogée : _____
(lien de parenté)

Profession du père : _____

Profession du mère : _____

Langue parlée: _____

À L'USAGE DU BUREAU SEULEMENT

Score – Motricité globale: ____ Numéros des énoncés: ____/____/____/____/____

Score – Motricité fine: ____ Numéros des énoncés: ____/____/____/____/____

Score – Psychosocial: ____ Numéros des énoncés: ____/____/____/____/____

Score – Symptômes: ____ Numéros des énoncés: ____/____/____/____/____

Score – Douleur: ____ Numéros des énoncés: ____/____/____/____/____

SECTION 1 -- ASPECTS DE LA MOTRICITÉ GLOBALE

A. Au cours des **2 DERNIÈRES SEMAINES**, avez-vous/votre enfant eu de la difficulté avec les activités suivantes **À CAUSE DE L'ARTHRITE OU DU TRAITEMENT**? Veuillez répondre à tous les énoncés (de 1 à 17) selon l'échelle suivante, en encerclant le chiffre correspondant à votre réponse.

Si votre enfant est trop jeune pour ces activités OU si vous entant que patient, ne faites pas ces activités, veuillez encercler le 0 – ne s'applique pas.

ÉCHELLE D'ÉVALUATION

0 = Ne s'applique pas à moi/mon enfant

1 = En aucun temps	- JAMAIS
2 = Presque jamais	- 10 % du temps
3 = Un peu	- 25 % du temps
4 = La moitié du temps	- 50 % du temps
5 = La plupart de temps	- 75 % du temps
6 = Presque tout le temps	- 90 % du temps
7 = Tout le temps	- TOUJOURS

1	Sortir du lit au réveil	0	1	2	3	4	5	6	7
2	Entrer dans la douche ou le bain, ou en sortir	0	1	2	3	4	5	6	7
3	Se laver, se peigner ou se brosser les cheveux	0	1	2	3	4	5	6	7
4	Mettre ses sous-vêtements, une jupe ou un pantalon	0	1	2	3	4	5	6	7
5	Mettre un chandail ou un manteau	0	1	2	3	4	5	6	7
6	Marcher sur une surface plate sur une distance d'un demi pâté de maisons ou marcher sur une surface plate ou inclinée	0	1	2	3	4	5	6	7
7	Monter ou descendre 10 marches	0	1	2	3	4	5	6	7
8	Courir sur une distance de								

2 pâtés de maisons 0 1 2 3 4 5 6 7

SECTION 1 -- ASPECTS DE LA MOTRICITÉ GLOBALE - suite

ÉCHELLE D'ÉVALUATION

0 = Ne s'applique pas à moi/mon enfant

1 = En aucun temps	- JAMAIS
2 = Presque jamais	- 10 % du temps
3 = Un peu	- 25 % du temps
4 = La moitié du temps	- 50 % du temps
5 = La plupart de temps	- 75 % du temps
6 = Presque tout le temps	- 90 % du temps
7 = Tout le temps	- TOUJOURS

9	Faire de la bicyclette (tricycle)	0	1 2 3 4 5 6 7
10	Pratiquer son sport favori (lequel ? _____)	0	1 2 3 4 5 6 7
11	Participer au cours d'éducation physique	0	1 2 3 4 5 6 7
12	Se pencher et soulever un objet de sol	0	1 2 3 4 5 6 7
13	S'agenouiller ou s'asseoir sur ses talons pendant quelques minutes	0	1 2 3 4 5 6 7
14	Rester assis pendant 30 minutes	0	1 2 3 4 5 6 7
15	Tourner la tête pour regarder par-dessus l'épaule	0	1 2 3 4 5 6 7
16	Mâcher ou avaler des aliments	0	1 2 3 4 5 6 7
17	Rester debout pendant 30 mintues	0	1 2 3 4 5 6 7

B. Maintenant, dans cette liste de 17 énoncés, indiquez les 5 énoncés qui présented le plus de difficultés pour votre enfant/vous, en encerclant le numéro de l'énoncé à gauche. Si vous ne pouvez en choisir 5, veuillez en indiquer le plus possible (maximum 5).

SECTION 1 -- ASPECTS DE LA MOTRICITÉ GLOBALE – suite

C. Si vous/votre enfant avez des difficultés avec d'autres aspects de la motricité globale qui n'ont pas été mentionnées, veuillez les décrire et indiquer le degré de difficulté comme précédemment.

_____	1	2	3	4	5	6	7
_____	1	2	3	4	5	6	7
_____	1	2	3	4	5	6	7

SECTION 2 -- ASPECTS DE LA MOTRICITÉ FINE

A. Au cours des 2 DERNIÈRES SEMAINES, avez-vous/votre enfant eu de la difficulté avec les activités suivantes À CAUSE DE L'ARTHRITE OU DU TRAITEMENT? Veuillez répondre à tous les énoncés (de 1 à 16) selon l'échelle suivante, en encerclant le chiffre correspondant à votre réponse.

Si votre enfant est trop jeune pour ces activités OU si vous, entant que patient, ne faites pas cette activité, veuillez encercler le 0 – ne s'applique pas.

ÉCHELLE D'ÉVALUATION

0 = Ne s'applique pas à moi/mon enfant

1 = En aucun temps	- JAMAIS
2 = Presque jamais	- 10 % du temps
3 = Un peu	- 25 % du temps
4 = La moitié du temps	- 50 % du temps
5 = La plupart de temps	- 75 % du temps
6 = Presque tout le temps	- 90 % du temps
7 = Tout le temps	- TOUJOURS

1	Ouvrir et fermer les robinets	0	1	2	3	4	5	6	7
2	Se brosser les dents	0	1	2	3	4	5	6	7
3	Mettre ses bas	0	1	2	3	4	5	6	7
4	Mettre ses souliers	0	1	2	3	4	5	6	7
5	Attacher ses souliers	0	1	2	3	4	5	6	7
6	Mettre une chemise ou une blouse	0	1	2	3	4	5	6	7
7	Attacher les boutons d'une chemise ou d'un manteau	0	1	2	3	4	5	6	7
8	Mettre des gants	0	1	2	3	4	5	6	7
9	Tourner la poignée pour ouvrir une porte	0	1	2	3	4	5	6	7

SECTION 2 -- ASPECTS DE LA MOTRICITÉ FINE - suite

ÉCHELLE D'ÉVALUATION

0 = Ne s'applique pas à moi/mon enfant

1 = En aucun temps	- JAMAIS
2 = Presque jamais	- 10 % du temps
3 = Un peu	- 25 % du temps
4 = La moitié du temps	- 50 % du temps
5 = La plupart de temps	- 75 % du temps
6 = Presque tout le temps	- 90 % du temps
7 = Tout le temps	- TOUJOURS

10	Ouvrir une canette de boisson	0	1	2	3	4	5	6	7
11	Ouvrir un pot/bouteille (ouvert auparavant)	0	1	2	3	4	5	6	7
12	Lever une tasse et boire	0	1	2	3	4	5	6	7
13	Se servir d'une cuillère, d'un couteau ou d'une fourchette	0	1	2	3	4	5	6	7
14	Écrire avec un crayon ou un stylo, dessiner ou colorier avec un crayon ou peindre avec un petit pinceau	0	1	2	3	4	5	6	7
15	Se servir d'une gomme	0	1	2	3	4	5	6	7
16	Couper du papier avec des ciseaux	0	1	2	3	4	5	6	7

B. Maintenant, dans cette liste de 16 énoncés, indiquez les 5 énoncés qui présentent le plus de difficultés pour votre enfant/vous, en encerclant le numéro de l'énoncé à gauche. Si vous ne pouvez pas en choisir 5, veuillez en indiquer le plus possible (maximum 5).

SECTION 2 -- ASPECTS DE LA MOTRICITÉ FINE – suite

C. Si vous/votre enfant avez des difficultés avec d'autres aspects de la motricité fine qui n'ont pas été mentionnés, veuillez les décrire et indiquer le degré de difficulté comme précédemment.

_____	1	2	3	4	5	6	7
_____	1	2	3	4	5	6	7
_____	1	2	3	4	5	6	7

SECTION 3 -- ASPECTS PSYCHOSOCIAUX

A. Au cours des **2 DERNIÈRES SEMAINES**, avez-vous/votre enfant manifesté ces comportements ou ces humeurs **À CAUSE DE L'ARTHRITE OU DU TRAITEMENT**? Veuillez répondre à tous les énoncés (de 1 à 12) selon l'échelle suivante, en encerclant le chiffre correspondant à votre réponse.

Si votre enfant êtes trop jeune pour démontrer ces comportements, veuillez encercler 0 – ne s'applique pas.

ÉCHELLE D'ÉVALUATION

0 = Ne s'applique pas à moi/mon enfant

1 = En aucun temps	- JAMAIS
2 = Presque jamais	- 10 % du temps
3 = Un peu	- 25 % du temps
4 = La moitié du temps	- 50 % du temps
5 = La plupart de temps	- 75 % du temps
6 = Presque tout le temps	- 90 % du temps
7 = Tout le temps	- TOUJOURS

1	Désobéit à ses parents ou a un mauvais rapport avec ses parents	0	1	2	3	4	5	6	7
2	A un mauvais rapport avec ses frères et soeurs	0	1	2	3	4	5	6	7
3	A un mauvais rapport avec les autres enfants	0	1	2	3	4	5	6	7
4	Est méchant(e) envers les autres	0	1	2	3	4	5	6	7
5	Fréquente des enfants qui s'attirent des ennuis	0	1	2	3	4	5	6	7
6	Se dispute beaucoup	0	1	2	3	4	5	6	7
7	Demande beaucoup d'attention	0	1	2	3	4	5	6	7
8	Se fait taquiner beaucoup	0	1	2	3	4	5	6	7
9	Pleure beaucoup sans raison apparente	0	1	2	3	4	5	6	7

SECTION 3 -- ASPECTS PSYCHOSOCIAUX

ÉCHELLE D'ÉVALUATION

0 = Ne s'applique pas à moi/mon enfant

1 = En aucun temps	- JAMAIS
2 = Presque jamais	- 10 % du temps
3 = Un peu	- 25 % du temps
4 = La moitié du temps	- 50 % du temps
5 = La plupart de temps	- 75 % du temps
6 = Presque tout le temps	- 90 % du temps
7 = Tout le temps	- TOUJOURS

10	Est facilement jaloux(se)	0	1	2	3	4	5	6	7
11	Se plaint de se sentir seul(e)	0	1	2	3	4	5	6	7
12	Pense ou se plaint que personne ne l'aime	0	1	2	3	4	5	6	7
13	Est facilement frustré(e)	0	1	2	3	4	5	6	7
14	Est déprimé(e)	0	1	2	3	4	5	6	7
15	Se croit inutile ou inférieur(e)	0	1	2	3	4	5	6	7
16	Se sent triste	0	1	2	3	4	5	6	7
17	Manque l'école (pour des raisons autres que des rendez-vous)	0	1	2	3	4	5	6	7
18	Dérange en classe	0	1	2	3	4	5	6	7
19	Ne peut se concentrer pour de longues périodes	0	1	2	3	4	5	6	7
20	Désobéit à ses professeurs(es)	0	1	2	3	4	5	6	7

SECTION 3 -- ASPECTS PSYCHOSOCIAUX - suite

ÉCHELLE D'ÉVALUATION

0 = Ne s'applique pas à moi/mon enfant

1 = En aucun temps	- JAMAIS
2 = Presque jamais	- 10 % du temps
3 = Un peu	- 25 % du temps
4 = La moitié du temps	- 50 % du temps
5 = La plupart de temps	- 75 % du temps
6 = Presque tout le temps	- 90 % du temps
7 = Tout le temps	- TOUJOURS

21	Réussit mal à l'école	0	1	2	3	4	5	6	7
22	Ne finit pas les choses qu'il/elle commence	0	1	2	3	4	5	6	7

B. Maintenant, de cette liste de 22 énoncés, indiquez les 5 énoncés qui présentent le plus de difficultés pour votre enfant/vous en encerclant le numéro de l'énoncé à gauche. Si vous ne pouvez en choisir 5, veuillez en indiquer le plus possible (maximum 5).

C. Si vous/votre enfant avez des difficultés avec certaines comportements ou humeurs qui n'ont pas été mentionnés, veuillez les décrire et indiquer le degré de difficulté comme précédemment.

_____	1	2	3	4	5	6	7
_____	1	2	3	4	5	6	7
_____	1	2	3	4	5	6	7

SECTION 4 -- SYMPTÔMES

A. Au cours des **2 DERNIÈRES SEMAINES**, avez-vous/votre enfant eu les symptômes suivant **À CAUSE DE L'ARTHRITE OU DU TRAITEMENT**? Veuillez répondre à tous les énoncés (de 1 à 19) selon l'échelle suivante, en encerclant le chiffre correspondant à votre réponse.

Si votre enfant êtes trop jeune pour manifester ces symptômes, veuillez encercler le 0 – ne s'applique pas.

ÉCHELLE D'ÉVALUATION

0 = Ne s'applique pas à moi/mon enfant

1 = En aucun temps	- JAMAIS
2 = Presque jamais	- 10 % du temps
3 = Un peu	- 25 % du temps
4 = La moitié du temps	- 50 % du temps
5 = La plupart de temps	- 75 % du temps
6 = Presque tout le temps	- 90 % du temps
7 = Tout le temps	- TOUJOURS

1	Mauvais appétit	0	1	2	3	4	5	6	7
2	Lésions buccales	0	1	2	3	4	5	6	7
3	Nausées, vomissements	0	1	2	3	4	5	6	7
4	Douleurs abdominales	0	1	2	3	4	5	6	7
5	Brûlements d'estomac	0	1	2	3	4	5	6	7
6	Diarrhée	0	1	2	3	4	5	6	7
7	Constipation	0	1	2	3	4	5	6	7
8	Sang dans les selles	0	1	2	3	4	5	6	7
9	Douleurs aux yeux, yeux rouge	0	1	2	3	4	5	6	7

SECTION 4 – SYMPTÔMES – suite

ÉCHELLE D'ÉVALUATION

0 = Ne s'applique pas à moi/mon enfant

1 = En aucun temps	- JAMAIS
2 = Presque jamais	- 10 % du temps
3 = Un peu	- 25 % du temps
4 = La moitié du temps	- 50 % du temps
5 = La plupart de temps	- 75 % du temps
6 = Presque tout le temps	- 90 % du temps
7 = Tout le temps	- TOUJOURS

10	Éruptions ou problèmes de peau	0	1	2	3	4	5	6	7
11	Douleur en urinant	0	1	2	3	4	5	6	7
12	Sang dans l'urine ou l'urine foncée	0	1	2	3	4	5	6	7
12	Maux de tête	0	1	2	3	4	5	6	7
14	Fièvre	0	1	2	3	4	5	6	7
15	Force diminuée ou limitée	0	1	2	3	4	5	6	7
16	Raideur	0	1	2	3	4	5	6	7
17	Se fatigue facilement	0	1	2	3	4	5	6	7
18	Articulation enflée	0	1	2	3	4	5	6	7
19	Articulation sensible ou douloureuse	0	1	2	3	4	5	6	7

B. Maintenant, de cette liste de 19 énoncés, indiquez les 5 énoncés qui présentent le plus de difficulté pour votre enfant/vous en encerclant le numéro de l'énoncé à gauche. Si vous ne pouvez pas en choisir 5, veuillez en indiquer le plus possible (maximum 5).

SECTION 4 – SYMPTÔMES – suite

C. Si vous/votre enfant avez eu des symptômes qui n'ont pas été mentionnés, veuillez les décrire et indiquer le degré de difficulté comme précédemment.

_____	1	2	3	4	5	6	7
_____	1	2	3	4	5	6	7
_____	1	2	3	4	5	6	7

SECTION 5 – DOULEUR

1. **L'impression du parent ou du patient à propos de la douleur:**

a.) Veuillez mettre un X sur la ligne, à l'endroit qui correspond à l'intensité de la douleur ressentie au cours de la dernière semaine.

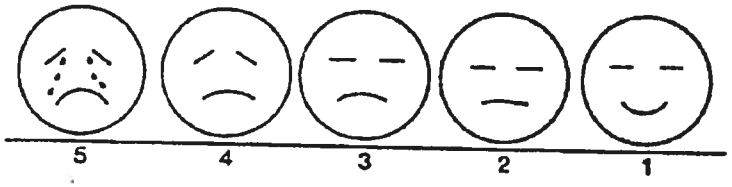
(0 = aucune douleur, 10 = la pire douleur)

0 _____ 10

b.) Si vous deviez employer des mots pour décrire la douleur (celle de votre enfant ou la votre) ressentie au cours de la dernière semaine, laquelle des expressions suivantes choisiriez-vous? Encerclez votre réponse.

aucune douleur douleur légère douleur moyenne douleur vive douleur extrême

c.) Si votre enfant a 10 ans ou moins, veuillez lui demander de choisir le dessin qui correspond à l'intensité de sa douleur, au cours de la dernière semaine.



2.) **Évaluation globale:** Depuis la dernière fois, vous/votre enfant vous sentez-vous:

1) Beaucoup mieux 2) Mieux 3) Pareil 4) Moins bien 5) Beaucoup moins bien

APPENDIX VII: SCL-90-R

Project: JIAStudy I
Form: SCLRQ
MCH I.D._____
Date: ___/___/___

INSTRUCTIONS:

Below is a list of problems and complaints that people sometimes have. Please read each one carefully. After you have done so, please circle one of the numbers to the right that best describes HOW MUCH DISCOMFORT THAT PROBLEM HAS CAUSED YOU DURING THE PAST WEEK INCLUDING TODAY. Circle only one number for each problem and do not skip any items. If you change your mind, erase your first mark carefully.

EXAMPLE
How much were you distressed by:

Bodyaches	0	1	2	③	4

HOW MUCH WERE YOU DISTRESSED BY:

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1. Headaches	0	1	2	3	4
2. Nervousness or shakiness inside	0	1	2	3	4
3. Repeated unpleasant thoughts that won't leave your mind	0	1	2	3	4
4. Faintness or dizziness	0	1	2	3	4
5. Loss of sexual interest or pleasure	0	1	2	3	4
6. Feeling critical of others	0	1	2	3	4
7. The idea that someone else can control your thoughts	0	1	2	3	4
8. Feeling others are to blame for most of your troubles	0	1	2	3	4
9. Trouble remembering things	0	1	2	3	4
10. Worried about sloppiness or carelessness	0	1	2	3	4
11. Feeling easily annoyed or irritated	0	1	2	3	4
12. Pains in heart or chest	0	1	2	3	4
13. Feeling afraid in open spaces or on the streets	0	1	2	3	4
14. Feeling low in energy or slowed down	0	1	2	3	4
15. Thoughts of ending your life	0	1	2	3	4
16. Hearing voices that other people do not hear	0	1	2	3	4
17. Trembling	0	1	2	3	4
18. Feeling that most people cannot be trusted	0	1	2	3	4
19. Poor appetite	0	1	2	3	4
20. Crying easily	0	1	2	3	4
21. Feeling shy or uneasy with the opposite sex					

Form:SCLRQ
Patient I.D.: _____

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
22. Feelings of being trapped or caught	0	1	2	3	4
23. Suddenly scared for no reason	0	1	2	3	4
24. Temper outbursts that you could not control	0	1	2	3	4
25. Feeling afraid to go out of your house alone	0	1	2	3	4
26. Blaming yourself for things	0	1	2	3	4
27. Pains in lower back	0	1	2	3	4
28. Feeling blocked in getting things done	0	1	2	3	4
29. Feeling lonely	0	1	2	3	4
30. Feeling blue	0	1	2	3	4
31. Worrying too much about things	0	1	2	3	4
32. Feeling no interest in things	0	1	2	3	4
33. Feeling fearful	0	1	2	3	4
34. Your feelings being easily hurt	0	1	2	3	4
35. Other people being aware of your private thoughts	0	1	2	3	4
36. Feeling others do not understand you or are unsympathetic	0	1	2	3	4
37. Feeling that people are unfriendly or dislike you	0	1	2	3	4
38. Having to do things very slowly to insure correctness	0	1	2	3	4
39. Heart pounding or racing	0	1	2	3	4
40. Nausea or upset stomach	0	1	2	3	4
41. Feeling inferior to others	0	1	2	3	4
42. Soreness of your muscles	0	1	2	3	4
43. Feeling that you are watched or talked about by others	0	1	2	3	4
44. Trouble falling asleep	0	1	2	3	4
45. Having to check and double-check what you do	0	1	2	3	4
46. Difficulty making decisions	0	1	2	3	4
47. Feeling afraid to travel on buses, subways, or trains	0	1	2	3	4
48. Trouble getting your breath	0	1	2	3	4
49. Hot or cold spells	0	1	2	3	4
50. Having to avoid certain things, places, or activities because they frighten you	0	1	2	3	4
51. Your mind going blank	0	1	2	3	4
52. Numbness or tingling in parts of your body	0	1	2	3	4
53. A lump in your throat	0	1	2	3	4
54. Feeling hopeless about the future					

Form: SCLRQ

Patient I.D.:_____

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
55. Trouble concentrating	0	1	2	3	4
56. Feeling weak in parts of your body	0	1	2	3	4
57. Feeling tense or keyed up	0	1	2	3	4
58. Heavy feeling in your arms or legs	0	1	2	3	4
59. Thoughts of death or dying	0	1	2	3	4
60. Overeating	0	1	2	3	4
61. Feeling uneasy when people are watching or talking about you	0	1	2	3	4
62. Having thoughts that are not your own	0	1	2	3	4
63. Having urges to beat, injure, or harm someone	0	1	2	3	4
64. Awakening in the early morning	0	1	2	3	4
65. Having to repeat the same actions such as touching, counting, or washing	0	1	2	3	4
66. Sleep that is restless or disturbed	0	1	2	3	4
67. Having urges to break or smash things	0	1	2	3	4
Having ideas or beliefs that others do not share	0	1	2	3	4
69. Feeling very self-conscious with others	0	1	2	3	4
70. Feeling uneasy in crowds, such as shopping or at a movie	0	1	2	3	4
71. Feeling everything is an effort	0	1	2	3	4
72. Spells of terror or panic	0	1	2	3	4
73. Feeling uncomfortable about eating or drinking in public	0	1	2	3	4
74. Getting into frequent arguments	0	1	2	3	4
75. Feeling nervous when you are left alone	0	1	2	3	4
76. Others not giving you proper credit for your achievements	0	1	2	3	4
77. Feeling lonely even when you are with people	0	1	2	3	4
78. Feeling so restless you couldn't sit still	0	1	2	3	4
79. Feelings of worthlessness	0	1	2	3	4
80. The feeling that something bad is going to happen to you	0	1	2	3	4
81. Shouting or throwing things	0	1	2	3	4
82. Feeling afraid you will faint in public	0	1	2	3	4
83. Feeling people will take advantage of you if you let them	0	1	2	3	4
84. Having thoughts about sex that bother you a lot	0	1	2	3	4
85. The idea that you should be punished for your sins	0	1	2	3	4
86. Thoughts and images of a frightening nature	0	1	2	3	4
87. The idea that something serious is wrong with	0	1	2	3	4

Form: SCLRQ
Patient I.D.:_____

	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
88. Never feeling close to another person	0	1	2	3	4
89. Feelings of guilt	0	1	2	3	4
90. The idea that something is wrong with your mind	0	1	2	3	4

Projet : SIA Étude I
Formulaire : SCLRQ
Identification MCH: _____
Date : ____/____/_____

Ci-dessous se trouve une liste de problèmes et de plaintes que les gens formulent de temps à autre. Lisez attentivement chacune de ces plaintes et cochez une des réponses décrivant le mieux jusqu'à quel point ce problème vous a dérangé durant les **sept derniers jours, aujourd'hui inclus.**

EXEMPLE : Jusqu'à quel point avez-vous été dérangé par :

	Pas du tout	Un peu	Modérément	Passablement	Énormément
1- Des maux de dos	X				

	Pas du tout	**Un peu**	**Modérément**	**Passablement**	**Énormément**
1- Des maux de tête					
2- La nervosité ou tremblement intérieur					
3- Des pensées désagréables qui vous reviennent constamment					
4- Des évanouissements ou des étourdissements					
5- Une perte d'intérêt ou de plaisir sexuel					
6- Une tendance à critiquer les autres					

Formulaire : SCLRQ
No. Identification : _____

	Pas du tout	Un peu	Modé-rément	Passa-blement	Énormé-ment
7- L'idée qu'un autre peut contrôler vos pensées	___	___	___	___	___
8- Le sentiment que les autres sont responsables de la plupart de vos problèmes	___	___	___	___	___
9- Ne pas se rappeler de certaines choses	___	___	___	___	___
10- Une préoccupation pour la malpropreté ou la négligence	___	___	___	___	___
11- Être facilement ennuyé(e) ou irrité(e)	___	___	___	___	___
12- Des douleurs au coeur ou à la poitrine	___	___	___	___	___
13- La peur des espaces ouverts ou de la rue	___	___	___	___	___
14- Le sentiment de manquer d'énergie ou d'être au ralenti	___	___	___	___	___
15- L'idée d'en finir avec la vie	___	___	___	___	___
16- Entendre des voix que les autres n'entendent pas	___	___	___	___	___
17- Des tremblements	___	___	___	___	___
18- Le sentiment que personne n'est digne de confiance	___	___	___	___	___

Formulaire : SCLRQ
No. Identification :_____

	Pas du tout	Un peu	Modé-rément	Passa-blement	Énormé-ment
19- Une perte d'appétit	___	___	___	___	___
20- Pleurer facilement	___	___	___	___	___
21- Un sentiment de gêne ou de malaise en présence de personnes de l'autre sexe	___	___	___	___	___
22- Le sentiment d'être pris(e) au piège	___	___	___	___	___
23- Une peur soudaine, sans raison	___	___	___	___	___
24- Des accès de colère que vous ne pouviez pas contrôler	___	___	___	___	___
25- La peur de sortir de la maison seul(e)	___	___	___	___	___
26- Une tendance à se reprocher des choses	___	___	___	___	___
27- Des douleurs au bas du dos	___	___	___	___	___
28- L'impression d'être incapable d'accomplir quoi que ce soit	___	___	___	___	___
29- Un sentiment de solitude	___	___	___	___	___
30- Avoir le cafard	___	___	___	___	___

Formulaire : SCLRQ
No. Identification :_____

	Pas du tout	Un peu	Modé-rément	Passa-blement	Énormé-ment
31- Trop s'inquiéter à propos de tout et de rien	___	___	___	___	___
32- Un manque d'intérêt pour tout	___	___	___	___	___
33- Un sentiment de crainte	___	___	___	___	___
34- Être plus susceptible	___	___	___	___	___
35- Les autres connaissent vos pensées intimes	___	___	___	___	___
36- Le sentiment que les autres ne vous comprennent pas	___	___	___	___	___
37- Le sentiment que les autres ne vous aiment pas	___	___	___	___	___
38- Faire les choses lente-ment pour s'assurer que tout est correct	___	___	___	___	___
39- Des palpitations ou le coeur qui bat très vite	___	___	___	___	___
40- Des nausées ou l'estomac dérangé	___	___	___	___	___
41- Un sentiment d'infériorité	___	___	___	___	___
42- Des muscles endoloris	___	___	___	___	___
43- Le sentiment qu'on vous observe ou que les autres parlent de vous	___	___	___	___	___

Formulaire : SCLRQ
No. Identification : _____

	Pas du tout	Un peu	Modé-rément	Passa-blement	Énormé-ment
44- De la difficulté à vous endormir	___	___	___	___	___
45- Le fait d'avoir à vérifier et revérifier ce que vous faites	___	___	___	___	___
46- De la difficulté à prendre des décisions	___	___	___	___	___
47- La peur de prendre l'autobus, le métro ou le train	___	___	___	___	___
48- De la difficulté à reprendre votre souffle	___	___	___	___	___
49- Bouffées de chaleur ou des frissons	___	___	___	___	___
50- Devoir éviter certaines choses, endroits ou activités parce que vous en avez peur	___	___	___	___	___
51- Le sentiment que votre esprit cesse de fonctionner momentanément	___	___	___	___	___
52- Une perte de sensation ou engourdissement dans certaines parties de votre corps	___	___	___	___	___
53- Une boule dans la gorge	___	___	___	___	___
54- Un sentiment de désespoir face à l'avenir	___	___	___	___	___

Formulaire : SCLRQ
No. Identification :_____

	Pas du tout	Un peu	Modé-rément	Passa-blement	Énormé-ment
55- Des difficultés de concentration	___	___	___	___	___
56- Une faiblesse dans certaines parties de votre corps	___	___	___	___	___
57- Se sentir tendu(e) ou nerveux(se)	___	___	___	___	___
58- Une sensation de lourdeur dans les bras ou les jambes	___	___	___	___	___
59- De penser à la mort ou à mourir	___	___	___	___	___
60- Trop manger	___	___	___	___	___
61- Se sentir mal à l'aise quand les autres vous regardent ou parlent de vous	___	___	___	___	___
62- Avoir des pensées étrangères à soi	___	___	___	___	___
63- Avoir envie de battre, blesser ou faire mal à quelqu'un	___	___	___	___	___
64- Se réveiller aux petites heures du matin	___	___	___	___	___
65- Avoir à répéter les mêmes gestes comme toucher, compter, laver	___	___	___	___	___
66- Passer des nuits blanches ou avoir le sommeil troublé	___	___	___	___	___
67- Avoir envie de briser ou casser des choses	___	___	___	___	___

Formulaire : SCLRQ
No. Identification :_____

	Pas du tout	Un peu	Modé-rément	Passa-blement	Enormé-ment
68- Avoir l'impression que les autres ne veulent pas partager	____	____	____	____	____
69- Se sentir très intimidé(e) par les autres	____	____	____	____	____
70- Se sentir mal à l'aise dans une foule comme au cinéma ou dans les magasins	____	____	____	____	____
71- Le sentiment que tout exige un effort	____	____	____	____	____
72- Des crises de frayeur ou de panique	____	____	____	____	____
73- Se sentir mal à l'aise de manger ou boire en public	____	____	____	____	____
74- Se disputer souvent	____	____	____	____	____
75- Se sentir nerveux(se) lorsque vous êtes laissé(e) seul(e)	____	____	____	____	____
76- Le sentiment qu'on ne reconnaît pas ce que vous accomplissez	____	____	____	____	____
77- Se sentir seul(e) même lorsque vous êtes avec d'autres	____	____	____	____	____
78- Se sentir si agité(e) que vous ne pouvez pas rester assis(e) tranquille	____	____	____	____	____

Formulaire : SCLRQ
No. Identification :_____

	Pas du tout	Un peu	Modé-rément	Passa-blement	Enormé-ment
79- Le sentiment de n'avoir aucune valeur	___	___	___	___	___
80- L'impression qu'un malheur va s'abattre sur vous	___	___	___	___	___
81- Crier et lancer des objets	___	___	___	___	___
82- Avoir peur de s'évanouir en public	___	___	___	___	___
83- Le sentiment que les gens vont profiter de vous si vous les laisser faire	___	___	___	___	___
84- Avoir pensées à propos du sexe qui vous troublent beaucoup	___	___	___	___	___
85- Le sentiment que vous méritiez être puni(e) pour vos péchés	___	___	___	___	___
86- Des idées ou des images qui vous font peur	___	___	___	___	___
87- L'idée que quelque chose de sérieux se passe dans votre corps	___	___	___	___	___
88- Ne jamais vous sentir proche d'une autre personne	___	___	___	___	___
89- Des sentiments de culpabilité	___	___	___	___	___
90- L'impression que ça va mal dans votre tête	___	___	___	___	___

APPENDIX VIII: CHQ-PF50

Child Health Questionnaire - Parent Report
CHQ-PF50

-INSTRUCTIONS-

1. This booklet asks about your child's health and well-being. Your individual answers will not be shared with anyone.

2. If you choose not to participate it will not affect the care you receive.

3. Answer the questions by marking the appropriate box ☑

4. Certain questions may look alike but each one is different. Some questions ask about problems your child may not have, but it's important for us to know that too. Please answer each question.

5. There are no right or wrong answers. If you are unsure how to answer a question, please give the best answer you can and make a comment in the margin

6. All comments will be read, so please feel free to make as many as you wish.

SECTION #1: YOUR CHILD'S GLOBAL HEALTH

1.1. In general, would you say <u>your child's health</u> is:

☐	☐	☐	☐	☐
Excellent	Very good	Good	Fair	Poor

SECTION #2: YOUR CHILD'S PHYSICAL ACTIVITIES

The following questions ask about physical activities your child might do during a day.

2.1. During the <u>past 4 weeks</u>, has your child been limited in any of the following activities due to <u>health problems</u>?

		Yes, limited a lot	Yes, limited some	Yes, limited a little	No, not limited
a.	Doing things that take a lot of energy, such as playing soccer or running?	☐	☐	☐	☐
b.	Doing things that take some energy such as riding a bike or skating?	☐	☐	☐	☐
c.	Ability (physically) to get around the neighborhood, playground, or school?	☐	☐	☐	☐
d.	Walking one block or climbing one flight of stairs?	☐	☐	☐	☐
e.	Bending, lifting, or stooping?	☐	☐	☐	☐
f.	Taking care of him/herself, that is, eating, dressing, bathing, or going to the toilet?	☐	☐	☐	☐

SECTION #3: YOUR CHILD'S EVERYDAY ACTIVITIES

3.1. During the past 4 weeks, has your child's school work or activities with friends been limited in any of the following ways due to EMOTIONAL difficulties or problems with his/her BEHAVIOR?

	Yes, limited a lot	Yes, limited some	Yes, limited a little	No, not limited
a. limited in the KIND of schoolwork or activities with friends he/she could do	☐	☐	☐	☐
b. limited in the AMOUNT of time he/she could spend on schoolwork or activities with friends	☐	☐	☐	☐
c. limited in PERFORMING schoolwork or activities with friends (it took extra effort)	☐	☐	☐	☐

3.2. During the past 4 weeks, has your child's school work or activities with friends been limited in any of the following ways due to problems with his/her PHYSICAL health?

	Yes, limited a lot	Yes, limited some	Yes, limited a little	No, not limited
a. limited in the KIND of schoolwork or activities with friends he/she could do	☐	☐	☐	☐
b. limited in the AMOUNT of time he/she could spend on schoolwork or activities with friends	☐	☐	☐	☐

SECTION #4: PAIN

4.1. During the past 4 weeks, how much bodily pain or discomfort has your child had?

☐	☐	☐	☐	☐	☐
None	Very mild	Mild	Moderate	Severe	Very severe

4.2. During the past 4 weeks, how often has your child had bodily pain or discomfort?

☐	☐	☐	☐	☐	☐
None of the time	Once or twice	A few times	Fairly often	Very often	Every/almost every day

SECTION #5: BEHAVIOR

Below is a list of items that describe children's behavior or problems they sometimes have.

5.1. How often during the past 4 weeks did each of the following statements describe your child?

		Very Often	Fairly Often	Sometimes	Almost Never	Never
a.	argued a lot	☐	☐	☐	☐	☐
b.	had difficulty concentrating or paying attention	☐	☐	☐	☐	☐
c.	lied or cheated	☐	☐	☐	☐	☐
d.	stole things inside or outside the home	☐	☐	☐	☐	☐
e.	had tantrums or a hot temper	☐	☐	☐	☐	☐

5.2. Compared to other children your child's age, in general would you say his/her behavior is:

☐	☐	☐	☐	☐
Excellent	Very good	Good	Fair	Poor

SECTION #6: WELL-BEING

The following phrases are about children's moods.

6.1. During the past 4 weeks, how much of the time do you think your child:

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. felt like crying?	☐	☐	☐	☐	☐
b. felt lonely?	☐	☐	☐	☐	☐
c. acted nervous?	☐	☐	☐	☐	☐
d. acted bothered or upset?	☐	☐	☐	☐	☐
e. acted cheerful?	☐	☐	☐	☐	☐

SECTION #7: SELF-ESTEEM

The following ask about your child's satisfaction with self, school, and others. It may be helpful if you keep in mind how other children your child's age might feel about these areas.

7.1. During the past 4 weeks, how satisfied do you think your child has felt about:

	Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied
a. his/her school ability?	☐	☐	☐	☐	☐
b. his/her athletic ability?	☐	☐	☐	☐	☐
c. his/her friendships?	☐	☐	☐	☐	☐
d. his/her looks/appearance?	☐	☐	☐	☐	☐
e. his/her family relationships?	☐	☐	☐	☐	☐
f. his/her life overall?	☐	☐	☐	☐	☐

SECTION #8: YOUR CHILD'S HEALTH

The following statements are about health in general.

8.1. How true or false is each of these statements for your child?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. My child seems to be less healthy than other children I know.	☐	☐	☐	☐	☐
b. My child has never been seriously ill.	☐	☐	☐	☐	☐
c. When there is something going around my child usually catches it.	☐	☐	☐	☐	☐
d. I expect my child will have a very healthy life.	☐	☐	☐	☐	☐
e. I worry more about my child's health than other people worry about their children's health.	☐	☐	☐	☐	☐

8.2. Compared to one year ago, how would you rate your child's health now:

☐	☐	☐	☐	☐
Much better now than 1 year ago	Somewhat better now than 1 year ago	About the same now as 1 year ago	Somewhat worse now than 1 year ago	Much worse now than 1 year ago

SECTION #9: YOU AND YOUR FAMILY

9.1. During the <u>past 4 weeks</u>, how MUCH emotional worry or concern did each of the following cause YOU?

	None at all	A little bit	Some	Quite a bit	A lot
a. Your child's physical health	☐	☐	☐	☐	☐
b. Your child's emotional well-being or behavior	☐	☐	☐	☐	☐
c. Your child's attention or learning abilities	☐	☐	☐	☐	☐

9.2. During the past 4 weeks, were you LIMITED in the amount of time YOU had for your own needs because of:

	Yes, limited a lot	Yes, limited some	Yes, limited a little	No, not limited
a. Your child's physical health?	☐	☐	☐	☐
b. Your child's emotional well-being or behavior?	☐	☐	☐	☐
c. Your child's attention or learning abilities?	☐	☐	☐	☐

9.3. During the past 4 weeks, how often has your child's health or behavior:

	Very often	Fairly often	Sometimes	Almost never	Never
a. limited the types of activities you could do as a family?	☐	☐	☐	☐	☐
b. interrupted various everyday family activities (eating meals, watching tv)?	☐	☐	☐	☐	☐
c. limited your ability as a family to "pick up and go" on a moment's notice?	☐	☐	☐	☐	☐
d. caused tension or conflict in your home?	☐	☐	☐	☐	☐
e. been a source of disagreements or arguments in your family?	☐	☐	☐	☐	☐
f. caused you to cancel or change plans (personal or work) at the last minute?	☐	☐	☐	☐	☐

9.4. Sometimes families may have difficulty getting along with one another. They do not always agree and they may get angry. In general, how would you rate your family's ability to get along with one another?

☐	☐	☐	☐	☐
Excellent	Very good	Good	Fair	Poor

SECTION #10: FACTS ABOUT YOUR CHILD

10.1. Is your child:

☐ Male

☐ Female

10.2. Was this your first child (natural or adopted)?

☐ Yes

☐ No

10.3. What is your child's date of birth?

☐☐ / ☐☐ / ☐☐

MONTH DAY YEAR

10.4. What is the highest grade of school your child has completed? (Circle one number only)

Preschool	☐	6th grade	☐
Kindergarten	☐	7th grade	☐
1st grade	☐	8th grade	☐
2nd grade	☐	9th grade	☐
3rd grade	☐	10th grade	☐
4th grade	☐	11th grade	☐
5th grade	☐	12th grade	☐
Ungraded	☐	If ungraded, how many years attended?	

10.5 Have you ever been told by a teacher, school official, doctor, nurse or other health professional that your child has any of the following conditions?

		Yes	No
a.	Anxiety problems	☐	☐
b.	Asthma	☐	☐
c.	Attentional problems	☐	☐
d.	Behavioral problems	☐	☐
e.	Chronic allergies or sinus trouble / Otitis / ear problems	☐	☐
f.	Chronic orthopaedic, bone or joint problems	☐	☐
g.	Chronic respiratory, lung or breathing trouble (NOT ASTHMA)	☐	☐
h.	Chronic rheumatic disease	☐	☐
i.	Depression	☐	☐
j.	Developmental delay or mental retardation	☐	☐
k.	Diabetes	☐	☐
l.	Epilepsy (seizure disorder)	☐	☐
m.	Hearing impairment or deafness	☐	☐
n.	Learning problems	☐	☐
o.	Sleep disturbance	☐	☐
p.	Speech problems	☐	☐
q.	Vision problems	☐	☐
r.	Does your child have any other chronic medical condition that is affecting what they do or how they feel? (Please describe below)	☐	☐
s.	Chronic gastrointestinal disease such as ileitis, colitis, inflammatory bowel disease or crohn's disease, hepatitis	☐	☐
t.	Chronic renal (kidney) disease such as nephrotic syndrome, nephritis or recurrent urinary tract infections	☐	☐

SECTION #11: FACTS ABOUT YOU

11.1. Are you:

☐ Male

☐ Female

11.2. What is your date of birth?

☐☐ / ☐☐ / ☐☐

MONTH DAY YEAR

11.3. Which of the following best describes your current work status? (Check all that apply)

☐ Not working due to my child's health

☐ Not working for "other" reasons

☐ Looking for work outside the home

☐ Working full or part time (either outside the home or at a home-based business)

☐ Full time homemaker

11.4. Which of the following best describes your relationship to your child?

☐ Biological parent

☐ Step parent

☐ Foster parent

☐ Adoptive parent

☐ Guardian

☐ Other (please explain on the line below)

_____

11.5. What is the highest grade of school you have completed?

☐ Some high school or less

☐ High school diploma/GED

☐ Vocational school or some college

☐ College degree

☐ Professional or graduate degree

11.6. Which of the following best describes your current marital status?

☐ Married ☐ Widowed ☐ Divorced ☐ Separated ☐ Remarried ☐ Never married

11.7. Which of the following best describes your racial background?

☐ Caucasian ☐ Afro-American ☐ Hispanic ☐ Asian/Oriental or Pacific Islander ☐ Other (please explain on the line below)

_____

11.8.What is today's date?

☐☐ / ☐☐ / ☐☐

MONTH DAY YEAR

THANK YOU FOR YOUR PARTICIPATION!

Questionnaire de Mesure de la Qualité de Vie des Enfants
Questionnaire des parents
CHQ-PF 50

- COMMENT RÉPONDRE -

1. **Ce livret contient des questions sur la santé et le bien-être de votre enfant. Vos réponses seront confidentielles.**

2. **Si vous choisissez de ne pas participer, cela n'affectera pas les soins que votre enfant recevra.**

3. **Pour répondre à une question, placez une croix dans la case de votre choix.**

4. **Certaines questions peuvent se ressembler mais en fait, elles sont toutes différentes. Certaines questions parlent de problèmes que votre enfant n'a peut-être pas, mais il est important pour nous de le savoir. Nous vous demandons de répondre à toutes les questions.**

5. **Il n'y a pas de bonnes ou de mauvaises réponses. Si vous n'êtes pas sûr(e) de comment répondre à une question, répondez du mieux que vous pouvez et mettez un commentaire dans la marge.**

6. **Vous pouvez mettre autant de commentaires que vous voulez. Ils seront tous lus.**

SECTION #1: LA SANTÉ GÉNÉRAL DE VOTRE ENFANT

1.1. En général, diriez-vous que <u>la santé de votre enfant est</u>:

☐	☐	☐	☐	☐
Excellente	Très bonne	Bonne	Pas très bonne	Mauvaise

SECTION #2: CE QUE VOTRE ENFANT EST CAPABLE DE FAIRE

Les questions suivantes portent sur les activités physiques que votre enfant fait peut-être au cours d'une journée normale.

2.1. Au cours des <u>4 dernières semaines</u>, votre enfant a-t-il été limité dans les activités physiques suivantes à cause de <u>problèmes de santé</u>?

		Oui, très limité	Oui, moyenne-ment limité	Oui, un peu limité	Non, pas limité
a.	Faire des choses qui demandent **beaucoup** d'énergie, comme jouer au soccer ou courir	☐	☐	☐	☐
b.	Faire des choses qui demandent une **certaine** énergie, comme se promener à bicyclette ou patiner	☐	☐	☐	☐
c.	Se déplacer (physiquement) dans le voisinage	☐	☐	☐	☐
d.	Faire un seul coin de rue ou monter un seul étage à pied	☐	☐	☐	☐
e.	Se pencher, s'accroupir ou se relever	☐	☐	☐	☐
f.	Manger, s'habiller, prendre un bain ou aller aux toilettes seul	☐	☐	☐	☐

SECTION #3: LES ACTIVITÉS QUOTIDIENNES DE VOTRE ENFANT

3.1. Au cours des 4 dernières semaines, votre enfant a-t-il été limité dans son travail scolaire ou ses activités avec des amis, de l'une ou l'autre des façons suivantes, à cause de problèmes ÉMOTIFS ou à cause de son COMPORTEMENT ?

	Oui, très limité	Oui, moyenne-ment limité	Oui, un peu limité	Non, pas limité
a. Limité dans le **GENRE** de travail scolaire ou d'activités avec des amis qu'il a pu faire	☐	☐	☐	☐
b. Limité dans le **TEMPS** qu'il a pu consacrer à son travail scolaire ou à ses activités avec des amis	☐	☐	☐	☐
c. Limité dans la **RÉALISATION** de son travail scolaire ou de ses activités avec des amis (il lui a fallu des efforts supplémentaires)	☐	☐	☐	☐

3.2. Au cours des 4 dernières semaines, votre enfant a-t-il été limité dans son travail scolaire ou ses activités avec des amis, de l'une ou l'autre des façons suivantes, à cause de sa SANTÉ PHYSIQUE?

	Oui, très limité	Oui, moyenne-ment limité	Oui, un peu limité	Non, pas limité
a. Limité dans le **GENRE** de travail scolaire ou d'activités avec des amis qu'il a pu faire	☐	☐	☐	☐
b. Limité dans le **TEMPS** qu'il a pu consacrer à son travail scolaire ou à ses activités avec des amis	☐	☐	☐	☐

SECTION #4: LA DOULEUR

4.1. Au cours des 4 dernières semaines, votre enfant a-t-il ressenti des douleurs ou des malaises physiques?

☐	☐	☐	☐	☐	☐
Pas du tout	Un petit peu mal	Un peu mal	Moyennement mal	Beaucoup mal	Enormément mal

4.2. Au cours des 4 dernières semaines, à quelle fréquence votre enfant a-t-il ressenti des douleurs ou des malaises physiques?

☐	☐	☐	☐	☐	☐
Jamais	Une ou deux fois	Parfois	Souvent	Très souvent	Tous les jours ou presque

SECTION #5: COMPORTEMENTS DE VOTRE ENFANT

Voici une liste d'énoncés qui décrivent des comportements d'enfants ou des problèmes qu'ils éprouvent parfois.

5.1. Au cours des 4 dernières semaines, à quelle fréquence votre enfant a-t-il eu les comportements décrits dans chacun des énoncés suivants?

	Très souvent	Souvent	Parfois	Rare ment	Jamais
a. Se dispute beaucoup	☐	☐	☐	☐	☐
b. A de la difficulté à se concentrer ou à être attentif	☐	☐	☐	☐	☐
c. Dit des mensonges ou triche	☐	☐	☐	☐	☐
d. Vole des choses à la maison ou vole des choses ailleurs	☐	☐	☐	☐	☐
e. Pique des crises ou se fâche vite (est «soupe au lait»)	☐	☐	☐	☐	☐

5.2. Comparativement à d'autres enfants de son âge, diriez-vous qu'en général la façon dont votre enfant se comporte est :

☐	☐	☐	☐	☐
Excellent	Très bon	Bon	Passable	Mauvais

SECTION #6: BIEN-ÊTRE

Les énoncés qui suivent portent sur les humeurs et les sentiments de votre enfant.

6.1. Au cours des 4 dernières semaines, à quelle fréquence pensez-vous que votre enfant:

	Tout le temps	Souvent	Parfois	Rare ment	Jamais
a. A eu envie de pleurer	☐	☐	☐	☐	☐
b. S'est senti(e) seul(e)	☐	☐	☐	☐	☐
c. A eu l'air nerveux(euse)	☐	☐	☐	☐	☐
d. A eu l'air inquiet(ète), perturbé(e)	☐	☐	☐	☐	☐
e. S'est montré(e) joyeux(euse)	☐	☐	☐	☐	☐

SECTION #7: ESTIME DE SOI

Les énoncés suivants portent sur la satisfaction de votre enfant envers lui-même, l'école et les autres. Il est bon de ne pas oublier comment d'autres enfants du même âge peuvent se sentir à cet égard.

7.1. Au cours des 4 dernières semaines, dans quelle mesure pensez-vous que votre enfant a été content de:

	Très content	Plutôt content	Ni content ni mécontent	Plutôt mécontent	Très mécontent
a. Ses capacités à l'école	☐	☐	☐	☐	☐
b. Ses capacités dans les sports	☐	☐	☐	☐	☐
c. Ses amitiés	☐	☐	☐	☐	☐
d. Son apparence physique	☐	☐	☐	☐	☐
e. Ses rapports avec sa famille	☐	☐	☐	☐	☐
f. Sa vie en général	☐	☐	☐	☐	☐

SECTION #8: L'ÉTAT DE SANTÉ DE VOTRE ENFANT

Les énoncés suivants portent sur l'état de santé général de votre enfant.

8.1. Dans quelle mesure chacun des énoncés suivants est-il VRAI ou FAUX dans le cas de votre enfant?

	Tout à fait vrai	Assez vrai	Ni vrai, Ni faux	Plutôt faux	Complè-ment faux
a. Mon enfant semble être en moins bonne santé que d'autres enfants que je connais	☐	☐	☐	☐	☐
b. Mon enfant n'a jamais été gravement malade	☐	☐	☐	☐	☐
c. Habituellement, mon enfant attrape tout ce qui passe	☐	☐	☐	☐	☐
d. Je m'attends à ce que mon enfant soit en très bonne santé durant sa vie	☐	☐	☐	☐	☐
e. Je suis plus inquiet(ète) que la moyenne des gens quand il s'agit de la santé de mon enfant	☐	☐	☐	☐	☐

8.2. <u>Par comparaison à l'an dernier</u>, comment évaluez-vous maintenant la santé de votre enfant?

☐	☐	☐	☐	☐
Bien meilleure maintenant que l'an dernier	Un peu meilleure maintenant que l'an dernier	À peu près la même que l'an dernier	Un peu moins bonne maintenant que l'an dernier	Bien moins bonne maintenant que l'an dernier

SECTION #9: VOUS ET VOTRE FAMILLE

9.1. Au cours des <u>4 dernières semaines</u>, dans quelle mesure les choses suivantes VOUS ont-elles (à vous parent) causé de l'anxiété ou de l'inquiétude?

	Pas du tout	Un peu	Moyen-nement	Beau-coup	Énor-mément
a. La santé physique de votre enfant	☐	☐	☐	☐	☐
b. L'état émotionnel de votre enfant	☐	☐	☐	☐	☐
c. L'attention ou les capacités d'apprentissage de votre enfant	☐	☐	☐	☐	☐

9.2. Au cours des 4 dernières semaines, le temps que VOUS (parent) avez consacré à vos propres besoins a-t-il été LIMITÉ à cause de:

	Oui, très limité	Oui, moyennement limité	Oui, un peu limité	Non, pas limité
a. La santé physique de votre enfant	☐	☐	☐	☐
b. L'état émotionnel de votre enfant	☐	☐	☐	☐
c. L'attention ou les capacités d'apprentissage de votre enfant	☐	☐	☐	☐

9.3. Au cours des 4 dernières semaines, est-ce que la santé ou le comportement de votre enfant:

	Très Souvent	Souvent	Parfois	Un peu	Jamais
a. a limité les types d'activités que vous auriez pu faire en famille	☐	☐	☐	☐	☐
b. a interrompu des activités familiales de tous les jours (prendre les repas, regarder la télé)	☐	☐	☐	☐	☐
c. a limité la possibilité pour votre famille de partir rapidement et à l'imprévu	☐	☐	☐	☐	☐
d. a été une source de tension et de conflit dans votre foyer	☐	☐	☐	☐	☐
e. vous a rapproché en tant que famille	☐	☐	☐	☐	☐
f. a été la raison pour laquelle vous avez annulé ou changé vos plans (personnels ou au travail) à la dernière minute	☐	☐	☐	☐	☐

9.4. Parfois, les membres d'une famille peuvent avoir de la difficulté à bien s'entendre les uns avec les autres. Ils ne sont pas toujours d'accord et peuvent se mettre en colère. En général, comment évaluez-vous la capacité des membres de votre famille à bien s'entendre les uns avec les autres?

☐	☐	☐	☐	☐
Excellente	Très bonne	Bonne	Passable	Mauvaise

SECTION #10: A PROPOS DE VOTRE ENFANT

10.1. Votre enfant est du sexe:

☐ Masculin ☐ Féminin

10.2. Est-ce votre premier enfant (biologique ou adopté)?

☐ Oui ☐ Non

10.3. Quelle est la date de naissance de votre enfant?

☐☐ / ☐☐ / ☐☐

JOUR MOIS ANNÉE

10.4. Quel niveau scolaire votre enfant a-t-il terminé? (cochez un seul choix)

Pré-maternelle	☐	6ième	☐
maternelle	☐	Secondaire 1	☐
1ère	☐	Secondaire 2	☐
2ième	☐	Secondaire 3	☐
3ième	☐	Secondaire 4	☐
4ième	☐	Secondaire 5	☐
5ième	☐	Autre	☐

Si autre, indiqué le nombre d'année de scolarité :_____

10.5 Est-ce qu'un professeur, le directeur de l'école, un médecin, une infirmière ou un autre professionel de la santé vous ont déjà dit que votre enfant a un des problèmes suivants:

		Oui	Non
a.	Problèmes d'anxieté	☐	☐
b.	Asthme	☐	☐
c.	Déficit d'attention	☐	☐
d.	Problèmes de comportement	☐	☐
e.	Allergies chroniques ou problèmes de sinus	☐	☐
f.	Problèmes orthopédiques, squelettiques, ou articulaires chroniques	☐	☐
g.	Problèmes respiratoires ou pulmonaires chroniques (AUTRES QUE L'ASTHME)	☐	☐
h.	Maladie arthritique chronique	☐	☐
i.	Dépression	☐	☐
j.	Retard de développement ou une déficience intellectuelle	☐	☐
k.	Diabète	☐	☐
l.	Epilepsie (attaques)	☐	☐
m.	Déficit auditif ou surdité	☐	☐
n.	Problèmes d'apprentissage	☐	☐
o.	Perturbation du sommeil	☐	☐
p.	Défauts d'élocution	☐	☐
q.	Déficit visuel	☐	☐
r.	Votre enfant a-t-il un autre problème de santé chronique qui influence ce qu'il fait ou comment il (elle) se sent? (Veuillez le décrire ci-bas.)	☐	☐

10.5 Est-ce qu'un professeur, le directeur de l'école, un médecin, une infirmière ou un autre professionel de la santé vous ont déjà dit que votre enfant a un des problèmes suivants:

		Oui	Non
a.	Problèmes d'anxieté	☐	☐
b.	Asthme	☐	☐
c.	Déficit d'attention	☐	☐
d.	Problèmes de comportement	☐	☐
e.	Allergies chroniques ou problèmes de sinus	☐	☐
f.	Problèmes orthopédiques, squelettiques, ou articulaires chroniques	☐	☐
g.	Problèmes respiratoires ou pulmonaires chroniques (AUTRES QUE L'ASTHME)	☐	☐
h.	Maladie arthritique chronique	☐	☐
i.	Dépression	☐	☐
j.	Retard de développement ou une déficience intellectuelle	☐	☐
k.	Diabète	☐	☐
l.	Epilepsie (attaques)	☐	☐
m.	Déficit auditif ou surdité	☐	☐
n.	Problèmes d'apprentissage	☐	☐
o.	Perturbation du sommeil	☐	☐
p.	Défauts d'élocution	☐	☐
q.	Déficit visuel	☐	☐
r.	Votre enfant a-t-il un autre problème de santé chronique qui influence ce qu'il fait ou comment il (elle) se sent? (Veuillez le décrire ci-bas.)	☐	☐

11.6. Lequel décrit le mieux votre statut marital?

☐	☐	☐	☐	☐	☐
Marié(e)	Veuf / Veuve	Divorcé(e)	Séparé(e)	Remarié(e)	Jamais marié(e)

11.7. Lequel de termes suivants décrit-il le mieux votre origine ethnique?

☐	☐	☐	☐	☐
Caucasien	Africain	Hispanique	Asiatique ou des Iles du Pacifique	Autre (veuillez spécifier sur la ligne suivante)

_____

11.8. Quelle est la date d'aujourd'hui?

☐☐	/	☐☐	/	☐☐
JOUR		MOIS		ANNÉE

Merci de votre participation!

APPENDIX IX: WeeFIM Score Sheet

WEEFIM SYSTEM (SM) - ASSESSMENT CODING FORM

VERSION 5.01

CASE IDENTIFICATION

1. Facility Code *
2. Patient Code *
3. Admission Date *

M M / D D / Y Y Y Y

ASSESSMENT INFORMATION

50. Assessment Type *
5-Baseline 1-Admission 2-Interim 3-Discharge 4-Follow-up

51. Assessment Date *
Enter date assessment performed
M M / D D / Y Y Y Y

52. Information Source
1-Staff 2-Parent 3-Caregiver 4-Patient 5-Other

53. Living Setting *
1-Home 2-Transitional living center 3-Skilled nursing facility 4-Died 5-Other

54. Living With
(only if living setting above is 1-Home)
1-Two parents 2-One parent 3-Relatives 4-Foster care 5-Shelter 6-Other

55. Educational Category
1-Not a student 2-Early intervention program 3-Preschool 4-Kindergarten through 12th 5-Other

56. Educational Setting
(only if educational category above is 2 to 4)
1-Regular class 2-Special class (approximately 12:1) 3-Special class (approximately 6:1) 4-Home-based 5-Day care/nursery school / Center-based / Community

FAMILY CENTERED FEEDBACK

57. Communications and Partnership
To what extent do the people who work with your child...

.1 discuss with you everyone's expectations for your child so that all agree on what is best?
1-Never 2-Sometimes 3-Frequently 4-Always

.2 make sure you have opportunities to explain what you think are important goals for your child?
1-Never 2-Sometimes 3-Frequently 4-Always

.3 make you feel like a partner in your child's care?
1-Never 2-Sometimes 3-Frequently 4-Always

58. Support and Advocacy
To what extent does the center where you receive services...

1 provide support to help you cope with the impact of childhood disability by advocating on your behalf?
1-Never 2-Sometimes 3-Frequently 4-Always

2 give you information about the types of services offered in your community?
1-Never 2-Sometimes 3-Frequently 4-Always

.3 satisfy your needs for family centered care?
1-Never 2-Sometimes 3-Frequently 4-Always

* Mandatory data item that must be completed for data transfer to UDSMR

59. WEEFIM (R) INSTRUMENT

	ASSESSMENT *	GOAL **
SELF-CARE		
.1 Eating		
.2 Grooming		
.3 Bathing		
.4 Dressing - Upper		
.5 Dressing - Lower		
.6 Toileting		
.7 Bladder		
.8 Bowel		
Self-care Total:		
Quotient:		
MOBILITY		
.9 Chair, Wheelchair		
.10 Toilet		
.11 Tub, Shower		
.12 Walk/Wheelchair		
.13 Stairs		
Mobility Total:		
Quotient:		
COGNITION		
.14 Comprehension		
15 Expression		
.16 Social Interaction		
17 Problem Solving		
.18 Memory		
Cognition Total:		
Quotient:		
WeeFIM Total:		
Quotient:		

W-Walk C-wheelChair L-crawL B-comBination

A-Auditory V-Visual B-Both

V-Vocal N-Nonvocal B-Both

Leave no blanks. Enter 1 if not testable due to risk.
** Data item is for facility use only and is not transferred to UDSMR.

WEEFIM RATING LEVELS

INDEPENDENT - No helper
No Assistance - "no hands on"
(Applicable to Self-Care and Mobility Domains)
7 Complete Independence (No device, timely and safely)
6 Modified Independence (Device, not timely or not safely)

DEPENDENT - Helper
5 Supervision or set-up (Subject = 100%)
Assistance - "Hands on"
(Applicable to Self-Care and Mobility Domains)
4 Minimal Assistance (Subject = 75% to 99%)
3 Moderate Assistance (Subject = 50% to 74%)
2 Maximal Assistance (Subject = 25% to 49%)
1 Total Assistance (Subject less than 25%)

Family Centered Feedback section is adapted from:
King, S., Rosenbaum, P., and King, G.,
The Measure of Processes of Care (MPOC),
A Means to Assess Family-Centered Behaviors of Health Care Providers

APPENDIX X: FES

Project:
HSJ ID:
Date:____/____/
dd mm yy

Family Empowerment Scale: Service System Dimension

Please score each of the following as follows:

1	2	3	4	5
not true at all	**slightly true**	**moderately true**	**almost completely true**	**completely true**

1. _____ I feel that I have a right to approve all services my child receives.
2. _____ I know the steps to take when I am concerned my child is receiving poor services.
3. _____ I make sure that professionals understand my opinions about what services my child needs.
4. _____ I am able to make good decisions about what services I want for my child.
5. _____ I am able to work with agencies and professionals to decide what services my child needs.
6. _____ I make sure I stay in regular contact with professionals who are providing services to my child.
7. _____ My opinion is just as important as professionals' opinions in deciding what services my child needs.
8. _____ I tell professionals what I think about services being provided to my child.
9. _____ I know what services my child needs.
10. _____ When necessary, I take the initiative in looking for services for my child and family.
11. _____ I have a good understanding of the service system that my child is involved in.
12. _____ Professionals should ask me what services I want for my child.

Projet:
No. d'identification HSJ: _____
Date: / /____
jj mm aa

Échelle d'empowerment familial: Dimension du Système de Service

S.V.P. veuillez utiliser l'échelle de cotation suivante pour indiquer votre réponse :

1	2	3	4	5
Tout à fait en désaccord	**Partiellement en accord**	**Modérément en accord**	**Presque entièrement d'accord**	**Tout à fait d'accord**

1. _____ Je pense que j'ai le droit d'approuver tous les services que mon enfant reçoit.
2. _____ Je connais les démarches à entreprendre lorsque j'ai l'impression que mon enfant reçoit de mauvais services.
3. _____ Je m'assure que les professionnels comprennent mon opinion quant aux besoins de services de mon enfant.
4. _____ Je suis capable de prendre de bonnes décisions concernant les services dont mon enfant à besoin.
5. _____ Je suis capable de travailler avec les organismes et les professionnels afin de décider quels sont les services dont mon enfant à besoin.
6. _____ Je m'assure de rester régulièrement en contact avec les professionnels qui offrent des services à mon enfant.
7. _____ Mon opinion est tout aussi importante que celle des professionnels dans la décision concernant les services dont mon enfant à besoin.
8. _____ Je dis aux professionnels ce que je pense des services qui sont fournis à mon enfant.
9. _____ Je sais de quels services mon enfant à besoin
10. _____ Quand c'est nécessaire, je prends l'initiative de chercher des services pour mon enfant et ma famille.
11. _____ J'ai une bonne compréhension de l'organisation des service qui s'adresse à mon enfant évolue.
12. _____ Les professionnels devraient me demander quels services je veux pour mon enfant.

APPENDIX XI: Co-authors Accord

ACCORD DES COAUTEURS ET PERMISSION DE L'ÉDITEUR

A) Déclaration des coauteurs d'un article

Lorsqu'un étudiant n'est pas le seul auteur d'un article qu'il veut inclure dans son mémoire ou dans sa thèse, il doit obtenir l'accord de tous les coauteurs à cet effet et joindre la déclaration signée à l'article en question. Une déclaration distincte doit accompagner chacun des articles inclus dans le mémoire ou la thèse.

1. Identification de l'étudiant et du programme

Sabrina Cavallo, Sciences Biomédicales, option Réadaptation

2. Description de l'article

Article #1.

Titre: Is Parental Coping Associated with Disease Severity in Juvenile Idiopathic Arthritis?

Auteurs: Sabrina Cavallo OT, BSc, Msc (cand); Bonnie Swinno PT, PhD; Garbis Mesrobefdjian PhD, Peter N. Malleson MBBS, MRCPUK, FRCPC, Ciarán M. Duffy, MB, BCh, MSc, FRCPC; Debbie Ehrmann Feldman PT, PhD.

3. Déclaration de tous les coauteurs autres que l'étudiant

À titre de coauteur de l'article identifié ci-dessus, je suis d'accord pour que Sabrina Cavallo inclue cet article dans son mémoire de maîtrise qui a pour titre "The impact of child's functional severity on parental coping in two cultures: children with juvenile idiopathic arthritis and [redacted] abilities".

[redacted]

Coauteur Signature

Coauteur Signature

[redacted]

ACCORD DES COAUTEURS ET PERMISSION DE L'ÉDITEUR

A) Déclaration des coauteurs d'un article

Lorsqu'un étudiant n'est pas le seul auteur d'un article qu'il veut inclure dans son mémoire ou dans sa thèse, il doit obtenir l'accord de tous les coauteurs à cet effet et joindre la déclaration signée à l'article en question. Une déclaration distincte doit accompagner chacun des articles inclus dans le mémoire ou la thèse.

1. Identification de l'étudiant et du programme

Sabrina Cavallo, Sciences Biomédicales, option Réadaptation

2. Description de l'article

Article #2.

Titre: Is Parental Coping Associated with Disease Severity in Children with Physical Disabilities?
Auteurs: Sabrina Cavallo OT, BSc, Msc (cand); Bonnie Swaine PT, PhD; Garbis Meshefedjian PhD, Debbie Ehrmann Feldman PT, PhD.

3. Déclaration de tous les coauteurs autres que l'étudiant

À titre de coauteur de l'article identifié ci-dessus, je suis d'accord pour que Sabrina Cavallo inclue cet article dans son mémoire de maîtrise qui a pour titre "The impact of child's functional severity on parental coping in two cohorts: children with juvenile idiopathic arthritis and children with physical disabilities".

[redacted]

Coauteur Signature Date

[redacted]

Coauteur Signature Date

[redacted]